

# **The Participation of Children with Disabilities**

**Thesis submitted as partial completion of the Master of Philosophy Degree in International Community Health**



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### **Presentation of the researcher**

The researcher is a 30 years old Norwegian nurse. I have travelled a lot around the world, visited more than 40 countries and worked at several places. For two years I was the project-representative for Norwegian Humanitarian Enterprise in Azerbaijan, working at orphanages for children with disabilities. In Norway, I have cared for children with disabilities at the children's departments at two hospitals in Oslo. After studying organisation and management for one year, I attended the two years Master programme at the University of Oslo, August 1999.

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### **Dedication**

The Masterthesis is dedicated to my dear fiancé Knut-Jarle who has patiently supported and encouraged me during my work with the thesis.

*Anne Johanne Retterholt*

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## **EXECUTIVE SUMMARY**

The research has touched on the need of assessing the situation of children with disabilities, which I have chosen to see in accordance with the official declaration of human rights. The Convention on the Rights of the Child and the Standard Rules are the most important rights and rules for children with disabilities worldwide. In Palestine, the Law of the Rights of the Disabled is another important tool in order to promote the active participation- and the equal rights of all.

The literature-review has identified that too little research has been done in the field of disability-studies. The literature indicates that in many countries, children with disabilities are found in poor and marginalised groups, not included in the community and not provided the mainstream health and social services. Poverty might lead to disability or disability might lead to poverty. However, some studies question the statements of children with disabilities being hidden and neglected. A problem is that researchers who have tried to document the situation often lack cultural knowledge and insight, which reflects the studies performed. It might be the situation that causes the attitudes, not the other way around. The financial, political and historical situation in the location must be seen in relation to the situation of people with disabilities.

The CBR programmes are said to be cost-effective and sustainable tools in order to promote equal opportunities for people with disabilities. One of the problems identified is the lack of impact studies and evaluations of CBR programmes. It is assumed that more research will be performed in the near future. Often the CBR programmes lack baseline-data, which makes it difficult to perform evaluations. This research might be used as a background of an evaluation of the CBR programme in Salfeet at a later stage.

The situation of children with disabilities in Palestine is strongly influenced by the political and economical situation in the country, which makes it very hard to improve the services. As the conflict is continuing, more people are hurt and killed and more people are in need of rehabilitation services.

The Law of the Rights of the Disabled in Palestine is an important tool, supporting the integration of people with disabilities into all parts of society.

The greatest resource in Salfeet is the people, in particular the family. Most families that I met are willing to do whatever it takes to improve the quality of life for their child with a disability. Most families with a disabled child feel that they have got little support from the rest of the community, both from the community members and from the Palestinian Authorities. The families ask for moral, financial and social support. Also the support and the communication between families with disabilities should be improved. At present there is no inclusive education programme or vocational training programme, and the health and social services are not covering the needs of the families with disabilities. Financial support is provided only in very special case, and it seems like the referral guidelines for the health services are not clear and the rehabilitation services are limited. All the local Ministries in Salfeet lack a plan to develop the services for children with disabilities at all sectors. However, when talking with them, they showed interest and willingness to improve the situation.

There are many resource persons in the local community. The General Union of the Palestinian Disabled in Salfeet is a resource organisation, being involved in the decision making process in Salfeet which is expected to have a long-term positive effect for people with disabilities in the local community.

Many children with disabilities seemed not to be included in the religious life of the community. The religious leaders are very influential in the Palestinian culture, and there is a need for them to be more involved in the improvement of the situation of people with disabilities.

It seems like children with mental disabilities and their families are facing the most difficult situation. The service provided at the Centre for Children with Disabilities is the only service available for children with mental disabilities. Children with Down syndrome are often put in institutions and they seem not to be integrated into the community.



Many people in Salfeet have little information about disabilities and an awareness-rising campaign is needed at all levels. This would reduce fear and insecurity, and make the integration process easier, and it would also promote the prevention of disabilities. Prevention of accidents at home and in the community would reduce the disability prevalence and incidence.

The physical environment in Salfeet is very polluted; the sewage-pipes from the Jewish settlement Ariel are polluting the water supply of Salfeet, the air is polluted by traffic and industry, and the land is polluted by littered. The Municipality is working on a new system for collecting waste, which is expected to have a positive effect.

In the Palestinian society, the women usually stay at home and take care of the children. When a child with a disability is born, she will get the main responsibility for caring for the child. Women are not represented- and lack influence in the decision-making process in Salfeet.

In general, it seems like there is a growing understanding of the needs of people with disabilities in Salfeet. Many people who showed great willingness and initiative to improve the situation impressed the researcher. The changing of attitudes and actions may take some time, but it is an ongoing process in Salfeet.

The CBR program faces many challenges in the time to come. The possibilities of implementing a sustainable CBR program depend on the political and economical development in the area. There is a need to improve the situation of children with disabilities at all levels, in the family and in the community: in the education sector, in the health-and social sector and in the religious life. Much may be achieved by awareness rising and by using the existing human and economical resources in Salfeet, giving increased participation of children with disabilities and a better situation of the families of these children.

## **1.0. INTRODUCTION**

Children's rights and the conditions of children with disabilities are very important issues to discuss and to work to improve. Children consist a vulnerable group, and should be cared for and protected at all levels of society. Because of personal experiences and interest, I wanted to focus on this issue when I attended the Master-programme at the University of Oslo.

The Master-programme, leading to a Master of Philosophy degree in International Community Health, is a two years programme. The first half-year gives a general theoretical background in the field of International Community Health, whereas the last one and half year of the study is focusing on the research of the individual student.

Rehabilitation is one of the themes in focus of the Master-programme. September 2000, the Norwegian Association of the Disabled (NAD) held a course about Community Based Rehabilitation/ CBR at the study. The course was led by Mr. Jens Mjaugedal from NAD, Mr. Allam Jarrarr, the Manager of the Northern CBR program at the West Bank, and Ms. Ghada Harami, the Manager of the Jerusalem office of the Swedish NGO Diakonia. The impact of the Palestinian CBR program seemed so impressing and interesting that I wanted to do the research in co-operation with this program. NAD, Diakonia and the Northern CBR program in Palestine helped preparing for the research and arranged for the fieldwork that took place in Salfeet, at the West Bank, September 1<sup>st</sup> - October 3<sup>rd</sup> 2000. I planned to stay longer, but because of the outbreak of the confrontations between the Palestinians and the Jews, I had to leave the research-site earlier than planned. After the fieldwork, I have worked with the analysis of the data collected in Salfeet and with the literature review of the study.

The Masterthesis consists partially of a literature study and partially of the results of the fieldwork. Both parts describe the possibilities of children with disabilities to participate in the family and in the local community. The intention is that the results of the fieldwork should be seen in relation to the literature that has been searched, and promote the human rights for children. The two parts of the thesis are strongly linked, but will be presented separately.

## **2.0. DESCRIPTION OF THE STUDY**

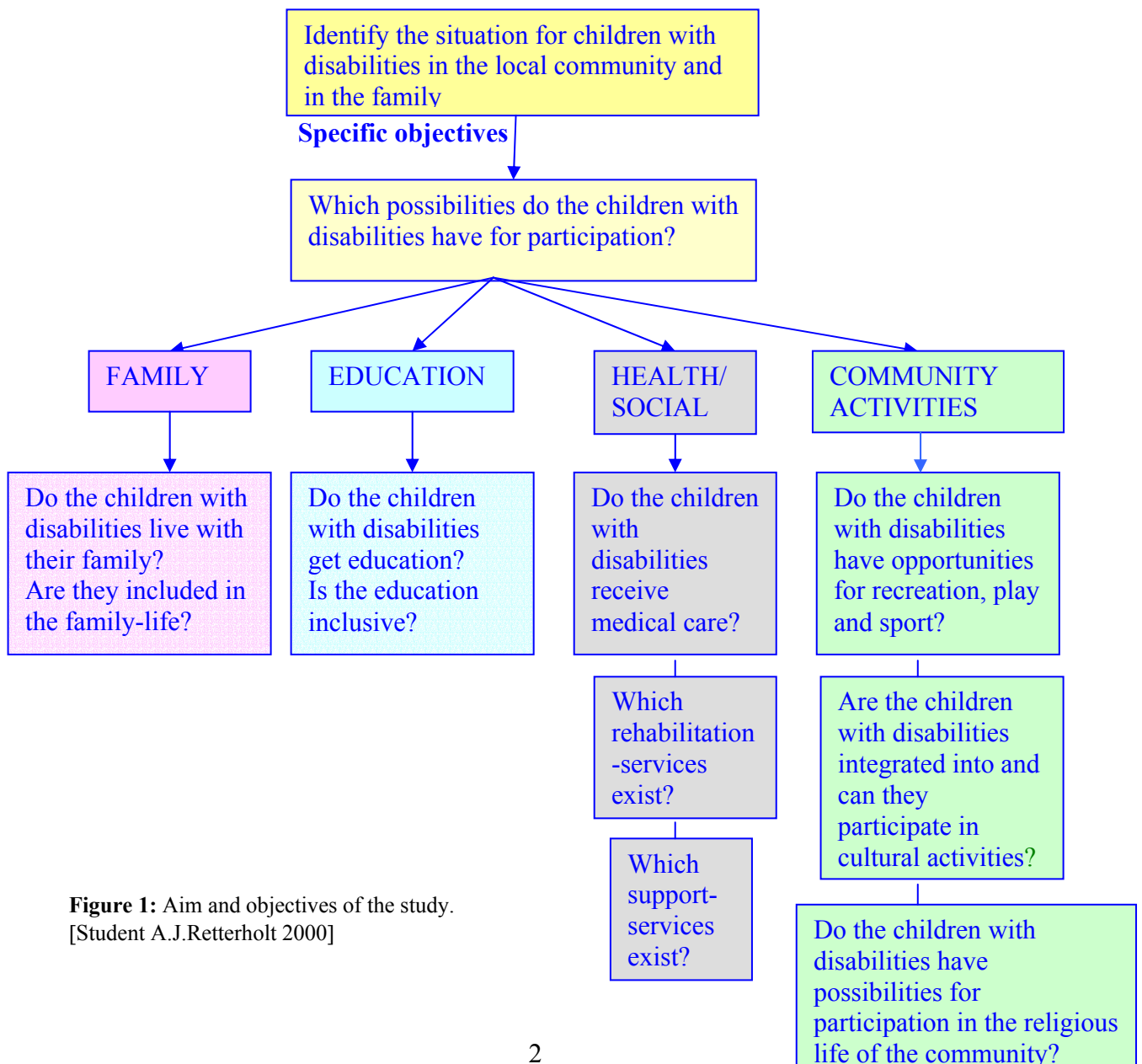
The Master thesis consists of two parts. The first part is a literature study and the second part is the results of the fieldwork.

### **2.1. Aim and objectives of the study**

#### **The ultimate aim of the study**

Identification of needs, ongoing processes and resources regarding children with disabilities in the study area will provide knowledge that the CBR- program may use as a foundation when expanding the services into this community.

#### **Superior objective**



**Figure 1:** Aim and objectives of the study.  
[Student A.J.Retterholt 2000]

This model is the basis of the hypothesis. The objectives are to identify the participation of children with disabilities in the family and in the community life, in education and in health and social service. This will identify new aspects of the situation of children with disabilities and state if the hypothesis is true or not.

## **2.2. Research site and study population**

The research site is a local community, Salfeet city at the West Bank. The Northern CBR-program has already performed a quantitative rapid assessment, and the CBR program has just been initiated in the city. The study population is the people in Salfeet, focusing on children with disabilities and their families.

## **2.3. Research question**

What are the possibilities for the children with disabilities in Salfeet to participate in the family and in the community?

## **2.4. Hypothesis**

The possibilities of children with disabilities to participate in the family are quite good, but the possibilities to participate in the local community are very limited.

## **2.5. Ethical considerations**

The Convention on the Rights of the Child (article 23) states the importance of a child's active participation in the community, and the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, rule 13, states the importance of researching the situation of children with disabilities (see no. 5.5.3 and appendix 11+13).

The research abides by the Declaration of Helsinki, taking into consideration the ethical aspects of human research (appendix 8). The researcher was aware that children with disabilities are a vulnerable group in society, and they are the main beneficiaries of this study. The research was performed in a respectful way regarding the person's autonomy and dignity. All informants were informed about the content and the use of the study

and about the interviews. The informants got an open choice whether they accepted to be interviewed or not. All informants gave a verbal informed consent to the interviews. The parents gave informed consent on the behalf of the children, but the children agreed to have the questions asked. The informant's names will not be used in the research, and some of the stories are slightly reconstructed. In some cases a fictitious name is given to the informant, and/or the sex of the informant might have been changed. Still, there is a danger that in a small community some of them might be recognised.

There is a need to do an in-depth study of the situation in Salfelt. This study identifies ongoing processes regarding children's participation that the CBR program can build on. The study is focusing on questions having practical importance in society. Because of the awareness rising and problem-identification nature of the study, one should be aware of the risk of creating expectations that cannot be fulfilled. In this case the study was performed in conjunctions with an intervention from the CBR program. Awareness rising followed by implementation of a sustainable CBR program intends to improve the quality of life for children with disabilities in the community. The study might be used by the CBR program and other organisations and institutions in the study area. The study may also be used as a background for an evaluation of the CBR-program at a later stage.

June 2000, the Norwegian Ethical Committee of Research "Den Norske Forskningsetiske Komité" approved this research.

### **3.0. STUDY METHODOLOGY**

This is a community study, identifying the situation of the children with disabilities and their families. Since this study is initiated in a pilot-phase of the CBR intervention and little is known about the situation of children with disabilities, qualitative method is chosen to identify the situation. Qualitative research is seeking to describe and to analyse the culture and behaviour from the point of view of those being studied, and it emphasises providing a “holistic” understanding of the social settings where the research is conducted.

Qualitative research is flexible; it is not fixed to a standard set of questions or to exclusively one specific approach to the research. Triangulation of data collection methods is used. Data triangulation (using different data sources) and methodological triangulation (using different data collection methods, like interview, observation etc) is used to increase the validity of the study. The research questions have been asked through a variety of interviewing-techniques, to different respondents. [WHO 1994: 54].

The study has a phenomenological approach. The intention is that the pre-knowledge of the researcher should not influence the communication with the informants. The important issue is to understand the life-situation of the persons being studied the way they look upon it and the way they feel themselves. The researcher listened to the precise descriptions of the informants, and the study intends to describe the central meaning of the communication [Kvale 1997: 40, 72]. The research is an assessment of the intervention development of the CBR program. It aims to give an answer to the research question, but it does not provide a full cultural understanding

#### **3.1. Literature review**

The first part of the research consists of the literature-review. Much literature about children with disabilities, children's Rights and about CBR has been found, and much research has been done in the field of rehabilitation, but they are all having a different focus compared with this study.

Different databases have been searched: BIBSYS, MEDLINE, the database of Redd Barna (Norwegian Save the Children), HDIP (Health Information Development Project) in Palestine and the DIS-database at Uppsala University, (Department of Paediatrics, International Child Health Unit).

NAD and AIFO (Dr. Deepak) has provided literature regarding CBR programs, and Rädda Barnen (Save the Children, Sweden, Ms. Persson) has provided a lot of useful information about Children's Right.

Save the Children UK (Ms. Stubbs) and Save the Children USA (Ms. Jones) have been contacted. Save the Children UK is planning to do a global evaluation of their CBR-programs in relation to the Rights of children with disabilities, but at this stage methodology for doing that has not been developed. Save the Children Jerusalem (Mr.Söderlind) has provided information regarding the children's rights in the area and about the Law of the Rights of the Disabled in Palestine.

Communication has also been established with Childwatch International in Oslo, Defence for Children International in Australia (Mr. Sandor) and Defence for Children in Jerusalem (Mr. Nougaret).

### **3.2. Interviews and observations**

The second part of the research consists the results of the fieldwork; the interviews and the observations made in Salfeet.

Interviews give knowledge about people's beliefs, attitudes, values and reported behaviour. At this research, semi-structured interviews were performed, based on the use of an interview guide (appendix 2 and 3). The interview-guide is a written list of questions or topics that are to be covered during the interviews, but the order and wording of the questions may vary. Case studies have been performed to collect comprehensive, systematic and in-depth information. This method helps to make sure that the person interviewed has commented on the subjects of interest. This method is flexible and gives freedom to discuss other topics and follow new leads as well.

Observations are useful to get information about the actual behaviour. Some behaviour involves habitual routines which people are hardly aware of. The observation helped the researcher to understand- and to put the behaviour in a context. At this study, non-participatory observations were performed. This means that the researcher was an on-looker rather than a participant observer. The persons observed knew they were observed, but what was actually observed was only broadly defined. The behaviour of children with disabilities, their families and other persons in the surroundings were observed in the local physical and social context.

Doing observations, there is always a danger of bias. People have limited capacity to observe everything that is going on in the moment and the researcher is influenced by her culture, upbringing and personal experience. To limit this bias, the observations were focused and systematic. [WHO 1994: 11-37]

### **3.3. Informants**

Children with disabilities and their families are the main informants. 11 children and their families were interviewed and some of them were visited several times. All the 5 schools in the city were visited and some of the children were observed at school.

12 public offices were visited and the Managers and some other employees were interviewed; at the Ministry of Social Affairs, the Ministry of Health/the Public Health Clinic, the Ministry of Education, the Ministry of Culture, the Ministry of Islamic Affairs, the Ministry of Youth and Sport, the Ministry of Labour, the Vocational Training Centre, the Mayor of Salfet, the Centre for Disabled Children in Salfet, the General Union of the Palestinian Disabled and the Jerusalem-office of Diakonia.

### **3.4. Sampling**

Non- probabilistic, purposeful sampling was used, which aims to give a theoretically representative sample of the study population by giving a great variation in the subject studied. Intensity sampling from a few selected cases provided information that describes the phenomena intensely. Using this method, groups of chosen informants or sites gives validity to the information and the findings may be generalised.



Study sites and informants were chosen to represent the different groups of children with disabilities. The CBR-worker already had a list of children with disabilities in the study area from a quantitative research performed by the CBR team, giving a description of the age, gender and the type of disability of the child. The research aims to have equal number of boys and girls included, and to represent children at different ages with various types of disabilities.

### **3.5. Interpretation**

A Palestinian lady, Mrs. Elham Joher was employed as an interpreter for the research. Mrs. Joher studied English literature in Kuwait and in Jordan, and she has worked as a translator in Jordan. As a Palestinian, she also provided valuable cultural information and understanding that the researcher benefited much from.

### **3.6. Field assistant**

The CBR worker, Ms. Senne Mansour, assisted me for the whole fieldwork-period, which was a great contribution from her- and from the Northern CBR-program. This gave the researcher an advantage of getting introduced to the informants easily, and the research could build on the trust that the CBR worker already had established.

### **3.7. Data analysis**

Doing qualitative research, the analysis often starts during the fieldwork. The researcher took notes and discussed issues that were analysed later. After all the interviews and the observations were written down and all information gathered, the formal data analysis-process started. At the first stage of the analysis, the data-reduction phase of the study, data gathered were simplified. All relevant sources of data were read through and considered before drawing any conclusions. Any differences or contradictions between data sources have been examined and explanations have been sought. If there has been a need for it, further investigations have taken place to clarify the situation. The researcher has made phone-calls, sent emails and discussed several issues with the CBR staff, the supervisors of the research and others. The Manager of the Northern CBR program in Nablus and the Manager of the Jerusalem office of Diakonia have got a copy of the

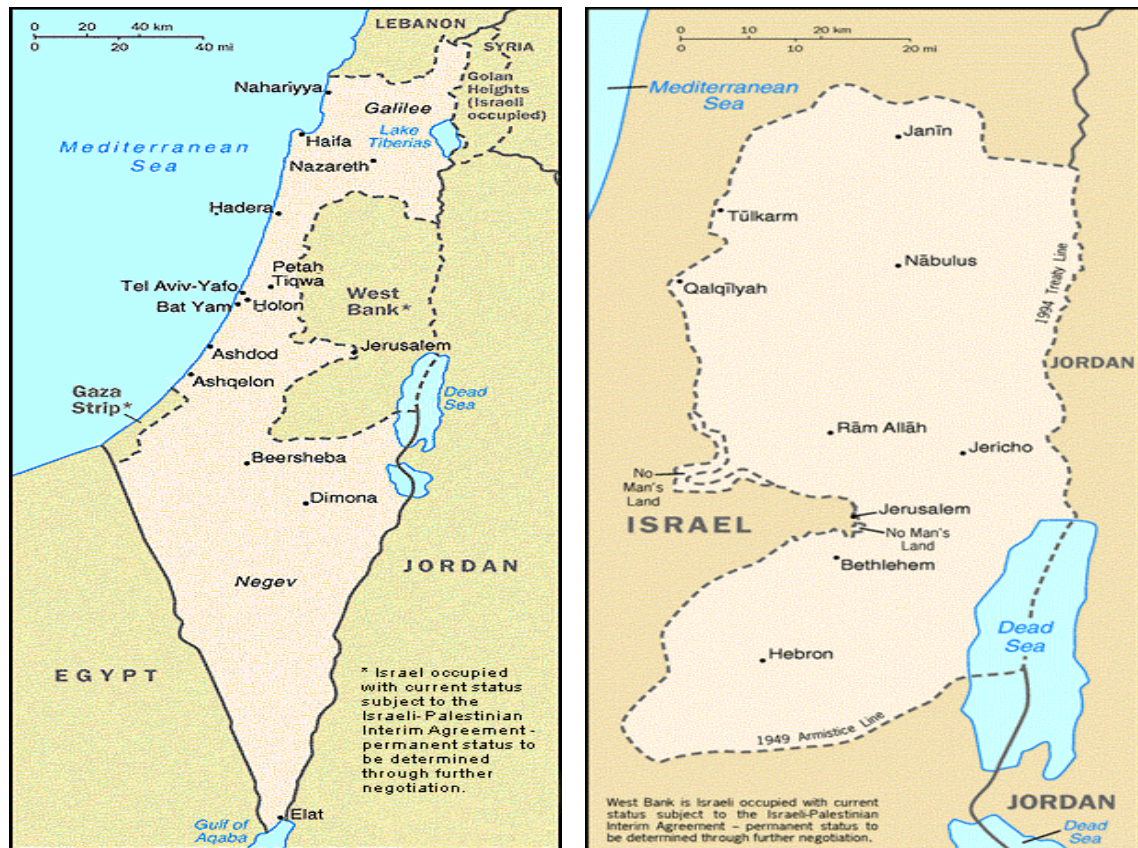
Masterthesis and a possibility to give their comments on the research before it has been finalised and printed.

In qualitative research, there is a risk of making generalisations based on only a few interviews or observations. It is important that the textual data is systematically analysed. To code the written notes is an approach to analyse textual data used in this study. A code is an abbreviation applied to a segment of text in order to classify and organise it. Codes are used to systematically organise and retrieve information relating to the different variables. This makes sure that all relevant data collected are used and the hypothesis may systematically be checked. At this study, computer software has not been used for analysing the data. [WHO 1994: 57-59]

By working with the data, the researcher has got a clearer picture of patterns and processes regarding the theme of the study. The intention is that the result of the research will reflect the views of those being studied and give new insight in the subject studied [Hellevik 1999: 195-198].

#### **4.0. PALESTINE**

This chapter is meant to identify the historical, political and economical situation in Palestine. These factors are closely linked to the situation of people with disabilities and the development of the CBR programme in the area.



**Figure 2: Map of Israel and the Palestinian Territories [Internet]**

The Palestinian Territories covers two main parts, Gaza (365 square km.) and the West Bank (5800 square km.). Parts of the territories are still under Israeli government (60%). The population density is high in Gaza (1400/square km.) and low at the West Bank (135/square km.).

99,8 % of the population of Gaza and the West Bank considers themselves as Palestinians. The British Mandate (1922) applied the term Palestinian to all inhabitants living east of the Jordan River whether Moslems, Christians or Jews. When the State of Israel was established in 1948 the official name of Palestine was dropped and from that time the term Palestinians began to refer only to Moslems and Christians living in the territories occupied by the State of Israel. The Political Dictionary of the State of Israel

identifies Palestinians as “*Arabs who resided in the territory of mandatory Palestine until the end of the British mandate in 1948*” [PNA 2000]. 90,3% of the Palestinians in Palestine are born inside Palestinian Territories [PCBS 1999: 38].

The official language in the area is Arabic. The majority of the people are Muslim, but there are some smaller groups of Christians and Jews and some other minority groups present.

Many Palestinians became refugees as a result of the 1948 and the 1967 war. Still there are about 2 million refugees in the neighbouring countries of Israel. Less than half of the refugees live in the refugee-camps. [Jareg *et al.* 1998:12]

	Palestinian Territories	Gaza Strip	West Bank
<b>% Refugees</b>	41,4 %	65,1%	26,5%
<b>No. of refugees</b>	1074718	651571	423147

**Table 1: Palestinian refugees.** [Heiberg 1993]

Good statistical data on the Palestinian population were held until 1994. The Jews had a good birth- and death register. When PLO arrived the country, Palestinians from the surrounding countries came to Palestine and many people decided to stay. The population growth led to a need for the demographic data to be renewed, and the Palestinian National Authorities entrusted Palestinian Central Bureau of Statistics (PCBS) with the census. The data was collected in 1997 and published in 1999 [PCBS 1999: 9].

#### **4.1. History**

The conflict between the Jews and the Arabs has deep historic and religious roots. Arabs and Jews as well as other people groups have lived in the area for centuries and both parts claim to be descendants from Abraham and to have the right to the country. The area became a British Mandate after the First World War, after being under Ottoman rule from the 15<sup>th</sup> century. The Balfour-declaration in 1917 supported the establishment of Palestine as a national home to the Jews, which resulted in a great immigration of Jews to Palestine during and after the Second World War.

November 1947, the UN suggested establishing both a Jewish and an Arab state (UN res.181). According to this plan 55% of the area should have been Israeli and 45% should have been Arabic. Jerusalem should have been an international entity with status as an international area, under the administration of the UN. The Arabs could not accept this and the Palestinian state has not been actualised according to this resolution.

November 29<sup>th</sup> 1947, the UN General Assembly passed a resolution calling for the establishment of a Jewish State in Israel. May 14<sup>th</sup> 1948 the Zionists proclaimed the State of Israel, which led to great opposition in the Arabic world. The Arabs declared a war that they later lost. Israel conquered the Negev-desert the same year, which divided the land of the Arabs into two parts. The Arabs in the newly established state Jordan kept the West Bank and East Jerusalem, Egypt controlled the Gaza strip and the Jews kept the other part. Israel established a passage to the Red Sea in 1956.

After the six-days war in 1967 Israel occupied the West Bank, including the rest of East Jerusalem, the Gaza Strip and the Golan-heights (belonging to Syria). The UN resolution 242 recognises these areas as the “Occupied Territories”. Resolution 242 call for just and lasting peace based on Israeli withdrawal, and respect for the rights and independence of every state in the area.

The Intifada, the Palestinian uprising started December 1987 and lasted for 5 years. It was a mass movement of civil disobedience and rebellion against the Israeli occupation. During the Intifada, there were mass demonstrations, strikes and boycotts of Israeli goods and services. The Intifada promoted national pride and unity among the Palestinians. The response was confrontations with Israeli Defence Forces, imprisonment, curfews, work and travel restrictions and school and university closures. [Save the Children 1997: 2]

#### **4.2. The peace process**



The Gulf-war and the weakened role of the Soviet Union led to a new situation in the Middle East. The Intifada also played an important role for convening a

**Figure 3: The peace process**

Peace conference. In 1988, the PLO officially endorsed the principles of a two state solution, based on UN resolution 242, thereby acknowledging the State of Israel. All these factors provided the basis for the peace-conference held in Madrid, 1991.

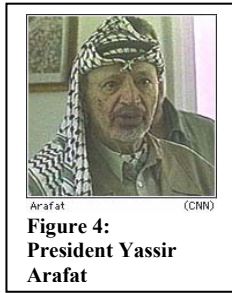
January 1993, secret negotiations between the two parts started up in Oslo. Gradually an agreement was made. August 1993, the Oslo agreement was officially announced. By this agreement, the Palestinians got autonomy in Gaza and in Jericho. The ultimate goal was to implement Security Council resolution 242.

The Declaration of Principles on Interim Self-government Arrangements was made in Oslo, but it was formally signed in Washington September 28<sup>th</sup> 1995. This agreement intended to give Israel and PLO a possibility to work together to establish peace. The Interim-agreement expanded the Palestinian autonomy at the West Bank through withdrawal of Israeli Defence Forces and having democratic elections in the Palestinian territories. According to the Interim agreement, the Israelis should leave the biggest cities at the West Bank; Jenin, Nablus, Qalqilya, Ramallah, Tulkarm and Bethlehem and they should leave 450 villages. When Israeli Defence Forces would withdraw, Palestinian police forces would take control. [UD 2000] [Heiberg *et al.* 1993: 37]

The negotiations on the permanent status arrangements commenced in Taba, Egypt, May 5<sup>th</sup> 1996. The final negotiations were supposed to deal with the most difficult issues to be resolved, including the status of Jerusalem, the refugees, the settlements, the security arrangements, the borders and the relations and the co-operation with the neighbouring countries.

The final peace agreement was supposed to be signed September 13<sup>th</sup> 2000. May 7<sup>th</sup> 2000, a summit was held in Ramallah at the West Bank. July 2000, the peace talks continued in Camp David, USA and in September 2000, negotiations were held at the UN summit in New York. No concrete results were seen and September 28<sup>th</sup> 2000, severe confrontations between the Palestinians and the Israelis started up again. At the “new Intifada”, a great number of people have been wounded and killed, especially on the Palestinian side. It is still not clear when and how this situation will end.

### **4.3. Palestinian Liberation Organisation, PLO**



PLO was established at an Arabic summit in Cairo in 1964. Yassir Arafat is the chairman of PLO, leading “al Fatah”, the major part of PLO. During the 1970’s, PLO emerged as the main representative of Palestinians and in 1974; Mr. Arafat was received at the UN General Assembly.

Mr. Arafat arrived Palestine July 1<sup>st</sup> 1994, and Palestinian National Authority (PNA) was established the same year. PNA took office in The Occupied Territories in 1995. The first Palestinian election was held in January 1996, where the Palestinian National Legislative Council was elected with Mr. Yassir Arafat as the president. [PLO 2000]. PNA has authority on less than 20% the ground they claim they have the right to have. [PNA 2000]

### **4.4. Demographic indicators**

<b>Population</b>	
Palestinian Territories	2895683
Male	1470506
Female	1425177
West Bank	1873476
The Gaza Strip	1022070
<b>Age distribution</b>	
0-4 years old	18,4%
5-14 years old	28,6%
15-64 years old	49%
65 years old and more	3,5%
Median age	16
<b>Education</b>	
Literate men over 15 years of age	91,7%
Literate women over 15 years of age	79%

School attendance 6-18 years of age	87,7%
<b>Economy</b>	
GNP per capita/year	1500\$
Total budget in Palestine/year	1 billion
Governmental expenditures on health/person	30-40\$
Governmental expenditures on health	9%
Governmental expenditures in social welfare	5%
Economically active	35,5%
Employed	82,1%
Monthly Consumption Per Capita	1547,7\$
Gross Domestic Product	4484,5 Million \$

**Table 2: Demographic indicators** [PCBS 2000]

### **4.5. Public services**

Before the Intifada, the Israeli Civil Administration and the United Nations Relief Work Association (UNRWA) organised and managed the services in the Palestinian territories. In addition, hundreds of local NGOs were providing services, especially in the field of



health, social service and education. NGOs have played a very important role in the process of developing Palestine. Until 1990, 90 % of the rehabilitation services were run by NGOs. Now there are four main service providers: government sector, non-governmental sector, UNRWA and private sector.

#### **4.6. Nablus**

This study is performed in Salfet, a local community in the Nablus-area. The map (fig.2) shows the location of Nablus, at the northern part of the West Bank, 66 km. north of Jerusalem. Nablus has 100396 inhabitants, and is the largest of the West Bank cities. The majority of the people are Muslims; the minority are Christians and Samaritans. The city came under Israeli occupation after the 1967 Arab-Israeli war. Nablus may be considered as one of the top cities in education; it has about 50 schools, including a university. The city has 4 hospitals and outside the city there are three refugee camps with 30000 inhabitants, built for the Palestinian refugees of 1948.

#### **4.7. Salfet**

Salfet city is the centre of a district with 20 villages. It has 21 populated zones with 70.000 inhabitants and a surface area amounting 218 square km. The city lies in the middle north of Palestine, between Nablus and Tel Aviv, the districts borders to Qalqilya, Nablus and Ramallah. Salfet is an old city, considered to be of the Kananite Era, and it has been a part of the Roman- and later of the Islamic Empire. In the Ottoman period, Salfet was a part of the Beirut State, and in 1882 it became the centre of the district. The Village Council was established in 1945 during the British Mandate. At the Jordanian Era (1952) it was transformed to Local Council and the Municipality of Salfet was established in 1955. After the establishment of the Palestinian National Authority in 1995, the district was promoted to “Salfet Governorate” in order to develop the area and protect it from Israeli settlements. From this time on, the ministries started to work in the city.

Salfet district has 17 Israeli settlements, the largest numbers of the districts at the West Bank. The biggest settlement is Ariel, by the Israelis considered the capital of Samaria.



Salfeet city is situated on a hill, on a beautiful location 570 metres above sea level. Salfeet depends economically on the olive cultivation and the stones. Besides, almond, grapevine, fruits and vegetables are grown. People also work in commerce, public services and government offices. People all over Salfeet district depend on trading with Nablus and on working in Israel. The unemployment rate is about 20%. The families have in average 5.8 children and most families belong to the middle class. There are four factories in Salfeet, for leather production, stone-cutting, granite-cutting and for olive-oil production. The leather factory is polluting very much, giving bad smell and releases chrome, zinc and other ingredients that may harm the skin of people.

[Salfeet web 2000] [Salfeet Municipality 2000]

## **Part 1: THE LITERATURE STUDY**

### **5.0. THE SITUATION OF CHILDREN WITH DISABILITIES**

The situation of children with disabilities in Palestine must be seen in a global context, it has many similarities to the situation of people with disabilities all over the world. This chapter will give an overview of the situation of children with disabilities in general, and of the situation in Palestine in particular. It also describes some of the rights and rules valid for children, especially children's right to health.



**Figure 5: A boy with a disability**

In 1995, WHO estimated that 245 millions, 6-7% of all persons in the world have a disability [Ingstad et al. 1995; 5]. The 1999 numbers were 500 millions. It is expected that the global population explosion will lead to an increasing number of people with disabilities; by 2025 the prevalence of disability is estimated to be 7,5%, 750 million people with disabilities.

Life expectancy is expected to increase and many people with disabilities will be elderly, often without traditional family support systems. The number of elderly people with a hearing and a seeing disability is expected to increase significantly. At the same time as people live longer; infants also survive at a younger age. The increasing number of wars and conflicts also contributes to the increasing number of people with disabilities.

[Disability'99 1999]

There is a strong link between poverty and disability. There is a lack of documentation of this issue, but it is estimated that one out of six people living in poverty also have a disability. In developing countries, the number is closer to one out of five persons. In order to eliminate poverty, one has to identify and strengthen the situation of people with disabilities. Experiences and smaller surveys show that the problem has two dimensions: poor people have greater risk of getting a disability and people with disabilities have greater risk of getting into poverty. Among the reasons why poor people have higher risk

of getting a disability is the lack of a balanced diet, unhealthy and unsafe living environment, low-paid, dangerous and insecure employment, exposure to violence, lack of access to health facilities and treatment and a high illiteracy rate which limits the access to information. In addition, poor people often lack influence and power in society. [Peat 1997: 10-11]

A study from Nairobi, Kenya points out that poverty is a risk factor of being disabled. The environment in Nairobi has many health dangers; overcrowded houses, polluted environment, alcohol abuse and prostitution were among the problems in the area. Lack of attention to emotional needs and early stimulation, security and protection during childhood made the learning- situation difficult at school. The attitudes towards persons with disabilities were negative and children with disabilities were hidden and neglected. [Ingstad *et al.* 1990: 17-25]

It is said that people with disabilities are often marginalised and they face problems like lack of education and income, and they have extra expenses as a result of the disability (technical advises, medicines etc.). In both industrialised and developing countries, they do often not receive sufficient medical and social services, and they are not included in other community activities and social gatherings. [Bruce 2000]

According to UNICEF, the prevalence of disabilities in developing countries is higher than in industrialised countries. This is said to be a result of the following factors:

- A great number of families living in poverty.
- Illiteracy and lack of knowledge about health, education and social welfare.
- Lack of knowledge about disabilities, the reasons for it and lack of treatment and prevention at all levels. This is often not prioritised by the national government.
- Lack of money, geographic distance to the services, social barriers is hindrances for using the available services.
- The services are often specialised and reaching only to a few people.
- Lack of or absence of services like health, education, social welfare and vocational training. [Bruce 2000]

People with disabilities are a vulnerable group and children with disabilities even more so. Children with disabilities have urgent needs that claim immediate action.

- *At least 150 million of the world's 500 million disabled persons are children.*
- *Only 3% of children with disabilities have access to rehabilitation and less than 2% of children with disabilities attend schools.*
- *Around 10% are expected to survive their twentieth birthday.*
- *About 80% of the world's disabled persons live in developing countries, mostly in poor rural areas.*
- *Only 1% of children with disabilities living in developing countries can count on any help.*

[Bergström 2000: 12]

Education of children with disabilities should be one of the main objectives to any state. It is estimated that 130 million children in developing countries can neither read nor write; the majority of these children are girls. About 3% of people with functional impairment can read whereas only 1% can both read and write.

### **5.1. Aspects on disability**

Disability has in general been looked upon very differently. Studies of the ancient Greeks, of pre-industrial Europe and of tribal people shows that disability was once regarded very differently from what it is now. The social process of disabling arrived with industrialisation and with the new set of practices and notions about nationality, race, gender, criminality etc. The word “normal” defined as “*constituting, conforming to, not deviating or different from, the common type or standard, regular, usual*” entered the English language around 1840. By definition, one can never have an ideal body. Each culture has its own perspective on normality and disability. [Davis 1997: 9-10] To have a disability cannot be seen as the contrary to being normal. The goal should be to enable all persons to maximise their potential, by giving equal opportunities for all.

There are different definitions and interpretations of the words disability, impairment and handicap, but this research will not go into that discussion. The researcher has chosen to use the term “person with disability” and the WHO definitions (appendix 5). The CBR concept is based on disability as a having a functional limitation or having activity restrictions.

Seeing disability in a cross-cultural perspective a person with a disability is “*a person who in his/her society is regarded as disabled, because of a difference in appearance and/or behaviour*”. [Helander 1993: 11] This definition is very wide. Giving a comprehensive picture of who are considered disabled in Salfeet would be a study of it's own. This research will only give some ideas of what consist a disability. In Salfeet the CBR workers have identified about 70 children with disabilities. At this study, the local CBR worker and the people in Salfeet themselves pointed out the informants. The researcher found the view of disability did not deviate a lot from the western view. The children pointed out as informants would have been defined as disabled in any western context. Taking into consideration the time limitation of the study, other views might be present but unknown to the researcher.

It has been said that the “myth” of the hidden and neglected disabled often becomes an excuse justifying paternalism and the righteousness of programs that often are made without communication with the people they concern; difficult life-conditions of the person could be the main problem, not the disability. Ingstad claims that persons with disabilities often are treated better and with more respect than western donor-organisations claim. Studies from East-Africa, Tanzania, Barbados, Nigeria, Zimbabwe, Somalia and Ethiopia shows that attitudes towards persons with disabilities vary greatly, from negative discrimination, to acceptance and even to the positive attribution of supernatural powers. One needs to understand the culture and the context to fully understand the meaning of how persons with disability are treated. [Ingstad 1989; 20-21]  
[Ingstad *et al.* 1995: 4, 260]

## **5.2. Identification of the situation of children with disabilities**



There is limited research done regarding the situation of people with disabilities in developing countries. The workshop “*Disability and Culture*” describes the situation of people with disabilities in different countries. Until the International Year of Disabled Persons in 1981, little was known about the situation. The main sources of knowledge of the situation prior to 1981 are folk tales and fairy tales, proverbs and information written down by missionaries and some early anthropologists. After the International Year of Disabled People, there has been an

increased awareness about the situation and needs of people with disabilities and several new rehabilitation programs, like CBR, have been developed. [Ingstad *et al.* 1990: 5-15]  
Many governments see rehabilitation, education and job placement of people with disabilities as expensive and non-productive. People with disabilities and their family often have little influence in society. The lack of equal opportunities may often be a serious threat to Human Rights. [Helander 1993: 87]

In Norway, there has recently been a discussion of the fact that people using wheelchairs cannot use public transportation and they have limited access to many public places. People with disabilities in all countries face many problems but in developing countries there are additional problems, often linked with lack of information and the lack of finances. The functional situation gives reduced level of performance of daily life activities, lack of education, lack of job and income, increased morbidity and mortality rate etc. The organisational problems leads to insufficient services, to lack of a local infrastructure for service delivery, lack of rehabilitation workers, low-functioning referral-service and co-ordination of the problems.

When starting up the CBR program in Botswana (1984), the first need identified for children were rehabilitation efforts aimed at reducing the immediate effect of the impairment. This could be physiotherapy, training in activities of daily living, mental stimulation and schooling. Withdrawal from the social life was not a common reaction among the people with disabilities interviewed. The disability lead to practical problems because of reduced mobility, but the wish to socialise with others and the feeling of being welcomed was present. People with disabilities were in many cases cared for in a good way, at least if they in some way could be useful in the household, they had a good chance of being accepted. [Ingstad 1997: ix, 20, 137, 163].

A participatory workshop held at the World Summit for Social Development in Copenhagen in 1995 revealed direct links between children with disabilities and poverty, productive employment and social integration. Participants drew attention to the invisibility of children with disabilities as a major obstacle in order to achieve social integration. The workshop focused on the vicious cycle of poverty and childhood disabilities. Children often suffer more from the social- than from the physical handicap, and social integration of children with disabilities through public awareness

and CBR programs should be the main objective in the years to come. Early detection was also seen as very important. 90% of disabilities are mild to moderate; if they are detected early they can be handled with minimal resources. [Parker 1995]

International Save the Children Alliance holds the opinion that many children with disabilities are excluded from society; the general exclusion factors are ignorance, negative attitudes and false beliefs towards them. Gender aspects are also of importance; a girl with a disability is suffering more than a boy. In poor communities, families with a person with a disability are often among the poorest and most marginalised; the family often becomes trapped in a cycle of poverty and exclusion. Because of these and other social and physical barriers children with disabilities are prevented from taking part in social events together with other children; their experience and the opportunity to develop through coping and learning from and with others are limited. Abuse and neglect are often the result of negative attitudes towards these children. Studies show that children with disabilities have more difficulties defending themselves than other children and are three times more likely to be sexually abused. [International Save the Children Alliance 1997]

According to Ingstad, the statements about “hiding” and “neglect” of people with disabilities in developing countries were used as propaganda for the International Year of Disabled Persons. To fully understand the way people treat persons with disabilities, their attitudes, beliefs and behaviour towards them, one needs to understand the culture and the context in which people are living. Often it is the political and economical situation in the location that causes the attitude that again is influencing the actions against people. Still there is a need for more in-depth studies to learn about the situation of persons with disabilities and their families as they experience it themselves, which would make it easier to understand the choices they make, why they accept offers of rehabilitation- or not, and how the persons with disabilities are cared for in the community and household etc. [Ingstad 1997: 5-13]

The book, *“The Participation Rights of the Child”* describes the right of children to take part in the society. The participation right and the right of self- expression, and the promotion and exercise of self-expression rights are discussed in details. Children with disabilities are not mentioned specifically, but the rights are the same if one has a disability or not. [Flekkøy *et al.* 1997]

October 1999, the Swedish organisation SHIA held a seminar about disability issues, focusing on women and children. SHIA is trying to map the situation of children with disabilities; mentally retarded children, children in institutions, children with visual and physical impairments and refugee-children. [Bergström 2000]

### **5.3. The situation of people with disabilities in Palestine**

<b>Persons with a disability</b>	<b>%</b>	<b>No.</b>
Palestinian Territories	1,8%	46063
The West Bank	1,6%	16214
The Gaza Strip	1,4%	16214
<b>Types of disability</b>		
Seeing	14,6%	
Hearing	5,1%	
Speaking	5,6%	
Mental	14,5%	
Moving	30,2%	
Hearing and speaking	6,4%	
Mental and moving	4,6%	
Multiple disabilities	7,9%	
Gripping	3,5%	
Other	7,6%	

**Table 3: Persons with disabilities in Palestine.** [PCBS 1999: 35-36]

According to NAD, the numbers are slightly different. 2-3 % of the total population are disabled and in need of rehabilitation services. 53 % of the disabled are males and 47 % are females. These numbers are contradicting the statements that many people with disabilities are men and boys, injured during the Intifada. More than 50 % of persons with disabilities are under the age of 12. Of all the disabilities, 30 % are physical, 30 % are sensory and 30 % are mental. 25-30 % of persons with disabilities have multiple disabilities. It is expected that the disability-rate will increase because of increased life expectancy. [Diakonia 2000].

The reason for the difference in statistical numbers at the Survey in 1997 and the numbers of NAD might be differences in the types of disabilities identified and the knowledge of the researchers. One assumption is that the CBR-workers might be better trained to



identify persons with a disability than researchers from the house-survey in 1997. There could also be differences in interpretation of what consist a disability.

Probably all the numbers are too low. According to the WHO, 6-7% of all people in the world have a disability and there is no reason to believe that this number is lower in Palestine. Because of the political and economical situation, one should rather believe that the percentage is higher.

About 10000 young people got a disability as a result of the Intifada; many of them were young men. This is approximately 10-12% of all persons with disabilities in Palestine prior to the confrontations that started September 2000. [Spadacini 2000: 6] Many persons who got a disability during the Intifada have a damaged spinal cord [Bergström 2000: 37].

The main causes of disability are genetic factors, conflict and war, relative's marriage, road accidents, chronic diseases and work-related accidents. [Harami 1999]

### **5.3.1. Children's mental health**

Children stood at the forefront during the Intifada, fighting and throwing stones on the Israeli soldiers. The children were beaten, shot, arrested and exposed to tear gas, they had their family and friends humiliated etc. After the Intifada, Gaza City Mental Health Program performed a survey of 2779 children. 92,5% of the children had been exposed to tear gas, 42% had been beaten, 55% had witnessed beating, 4,5% had their bones broken or had other severe injuries, 85% had been exposed to night raids and 19% had been detained for short periods of time. The psychological damage resulted in anxiety, depression, Post Traumatic Stress Disorder, hyperactivity, bedwetting, sleepwalking, night terror, nightmares etc. [El Sarraj 1993]

Today the children face new anxieties and stresses associated with difficult political and economic conditions and the despair resulting from unrealised dreams of peace [Gaza Community Mental Health Programme 1997: 32-33].

A research of 11-12 years old children in Gaza shows that the peace treaty led to decreased level of neurotics and increased self-esteem among them, only among the children who did not accept the peace treaty and did not participate in the following

celebrations and festivals neurotics increased and the self-esteem decreased [Quota *et al.* 1995: 1197].

#### **5.4. Stigma**

Stigma is culturally constructed and attitudes towards people with disabilities may vary from one community to another. Stigma is a negative attitude having to do with the interpersonal relations in a community. The expression originally comes from the Greeks, referring to bodily signs burned into the body to indicate that the person was unusual in a negative way, had a bad moral status etc. and should be avoided. Nowadays stigma occurs mainly because of abominations of the body, the individual character or because of the race, nationality or religion of the person. If a child with a disability is stigmatised, the stigma may spread to the family and others in the surroundings. [Davis 1997: 203]

According to Diakonia, the attitudes towards people with disabilities in Palestine have been charitable, as Moslem people are supposed to give charity to the poor and needy. Diakonia claims that people with a disability are often found in the poor social groups. Social stigma, negative attitudes and discrimination, especially against females have traditionally been an additional negative part of their living-conditions. People with a disability are not seen as a productive force; some have been hidden at secret places where nobody would know about them, they have suffered from isolation, marginalisation and oppression. The Intifada made a change, from this period on, young people with disabilities wounded during the Intifada were perceived as national heroes. [Harami 1999]

According to NAD, Palestinian women giving birth to a child with a disability is losing respect in the society. The mother is blamed and often the husband threatens to leave her. Many women feel they lose their honour and their value and this gives them an additional burden. [NAD 2000]

#### **5.5. The human right instruments for children**

The Rights of children with disabilities are stated especially in the Standard Rules on the Equalisation of Opportunities for persons with disabilities and in The Convention on the

Rights of the Child. All other Rights and Rules do also count for children with disabilities. There has been a lot of discussion about whether or not it is needed to have a separate rule for children with disabilities. The inclusion of a specific rule for children with disabilities reflects a growing understanding and acknowledgement of the links between disability and Human Rights.

Implementing the Rights and Rules for children is the ultimate aim that many nations are struggling to achieve. For countries facing difficult conditions politically and economically (like Palestine) it might take time to reach the goals. However, to be in a positive process will step by step lead the nations towards the full implementation of all the Rights. The Law of Disabled People in Palestine is an important step forward, showing that the Palestinians are heading in the right direction.

All the rights and rules valid for children with disabilities are individual-centred, reflecting the western individualistic society. There is a need to open up for a discussion whether or not this is suitable in a developing country. The Palestinian society is family-centred and the individual person is seen in relation to the family it belongs to. It is acknowledged that families and friends provide up to 90% of the care for people with disabilities who live at home. [Peat 1997: 118]

The researcher holds the opinion that the rights and the responsibilities should be more family-oriented in order to improve the conditions not only for the child with disability, but for the whole family. As an example, the family should have the right to information about the disability of the child, the treatment, habilitation or rehabilitation, the prognosis of the child and the family should have the right to support-services in order to bring up the child in the family.

#### **5.5.1. The Declaration on Human Rights**

The Declaration consists of the basic Human Rights and is seen as the most important document of the United Nations (UN Dec.10<sup>th</sup> 1948, appendix 10). This declaration set a common standard for all people, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, disability or other status.

The Declaration recognises the inherent dignity and equal rights of all people as a foundation of freedom, justice and peace in the world. Article 1 states that “ *all human beings are born free and equal in dignity and rights*”, matters that people with disabilities all around the world are struggling to achieve; the key to equalisation of opportunities for people with disabilities.

The Declaration recognises the family as the fundamental group of society. The right to social security, to rest and leisure, to participate in the cultural life of the community, to an adequate standard of living and the right to education is also a great concern to people with disabilities.

### **5.5.2. The Convention on the Rights of the Child**

The UN’ International Year of the Child in 1979 led to an establishment of a commission that started to develop a convention for children’s rights, seeing children as an especially vulnerable group that needs special protection. 10 years of work followed and 30 years after the Declaration of Human Rights, the Convention of the Rights of the Child was adopted (UN Nov. 20<sup>th</sup> 1989, appendix 11).

The Convention (article 1) defines a child to be a person under the age of 18. The Convention gives directions to the states, not to individuals. The Convention states that the parents have the main responsibility of the child, but the rights and rules of parents are stated in other laws. The foundation of the Convention is that childhood has it’s own value and should be protected. Children have rights and should be heard and have influence in society; the best interest of the child shall be a primary consideration in all actions taken. All children have the right to life, survival and development.

The Convention gives minimum standards; if national laws give better protection, these laws should be followed. Children’s Rights are the same regardless of which country you may live in. All UN countries except for the USA and Somalia have ratified the Convention on the Right of the Child. Even if the theoretical foundation is the same, practice may vary. Children’s standards- and way of living must be seen in relation to the context in which the children are living.

### **5.5.3. The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities**

“The Standard Rules” have been developed on the basis of the experience gained during the United Nations Decade of Disabled Persons 1983- 1992 (UN resolution Dec. 20<sup>th</sup> 1993, appendix 13). The 22 rules concern Rights, opportunities and responsibilities for people with disabilities and propose how governments can create an accessible society for all.

According to the rules, the pre-conditions for equal participation are awareness raising, medical care, rehabilitation and support services. The target areas for equal participation are accessibility of the community, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation, sports and religion.

Implementation measures are information and research, policy making and planning, legislation, economic policies, co-ordination of work, organisations of persons with disabilities, personnel training, national monitoring and evaluation of programmes in the implementation of the Standard Rules, technical and economic co-operation and international co-operation.

The Standard Rules are not compulsory or legally binding, but imply a strong moral and political commitment. The purpose is to ensure that persons with disabilities get the same Rights and obligations as others. Many countries have applied the Rules, and the Standard Rules are starting to be international customary rules [UNICEF 1998: 659].

It is proposed that the Standard Rules should be transformed into a convention and be more legally binding for the governments. It is also proposed that the Standard Rules should be improved and more focused on women and children with disabilities.[Bergström 2000: 6, 11]

The UN special Rapporteur, Mr. Bengt Lindqvist, has monitored the Standard Rules. The Standard Rules should have been revised year 2000, but this was not done. Mr. Lindqvist is preparing - in close co-operation with his Panel of Experts from the six major international NGOs – to develop a supplementation of the Rules that will be presented to the UN Commission for Social Development in the beginning of year 2002. [UN 2001]

## **5.6. Children's rights in Palestine**

The Convention cannot be ratified by Palestine, as it is not recognised as a state. Because of this there is no signature of the Convention on the Rights of the Child from an official Palestinian level. However, the Palestinian Legislative Council and President Yassir Arafat himself have expressed officially that they will sign and ratify the Convention as soon as Palestine reaches its legal status. That implies that in the territories under Palestinian jurisdiction the advocacy work of international and national NGOs follows the same patterns as if the authority was seen as an official, internationally recognised government.

Israel ratified the Convention on the Rights of the Child October 1991. The Convention covers all children within the boundaries of a nation. This means that the Israeli government has – with regards to the Convention- the responsibility over the Israeli territories with all their minorities as well as more than 70% of the territories occupied since the 1967 war. [Rädda Barnen 2000]

In the Interim-agreement (1995), both Israel and the PLO agreed to follow international accepted norms and principles for Human Rights and the rule of Law. [Nobel *et al.* 1997: 5-6] (PLO and Amnesty in Oslo also confirm this information.)

Palestine is one of the 22 members of the Arab-league that September 15<sup>th</sup> 1994 agreed on a Charter on Human Rights. According to Nobel, this Charter is not expected to get any great importance, it is incomplete and lacking important Human Rights-elements.

### **5.6.1. The Law of the Rights of the Disabled in Palestine**

Since 1993, the CBR program has lobbied for a law for people with disabilities. The General Union of the Palestinian Disabled (GUPD), the Central National Committee of Rehabilitation (CNCR) and 23 NGOs have all worked very hard on this task.

The law was ratified by President Arafat August 8<sup>th</sup> 1999 and was first published October 10<sup>th</sup> 1999 (Palestinian Legislative Council, Oct. 10<sup>th</sup>. 1999, appendix 12). The aim is to guarantee equity and a dignified life for persons with disabilities. Article 2 states that *“The disabled have the right to enjoy a free and dignified life and to enjoy all services.*

*He/she also has duties that are limited to his/her capabilities. His/her disability should not be the reason to withhold his/her rights”.*

The law states the responsibilities of the Ministry of Social Affairs regarding describing the extent and the nature of the disabilities and the effect the disabilities have on the families. The Ministry of Social Affairs is also responsible for awareness rising and for conducting care and rehabilitation in all fields.

According to the CBR-team in Nablus, there are various reasons why this law has not been implemented yet. It takes time to put the new regulations and norms into practice and there is a financial problem. The attitudes of the people must be changed, which is a slow, but ongoing process in the Palestinian society.

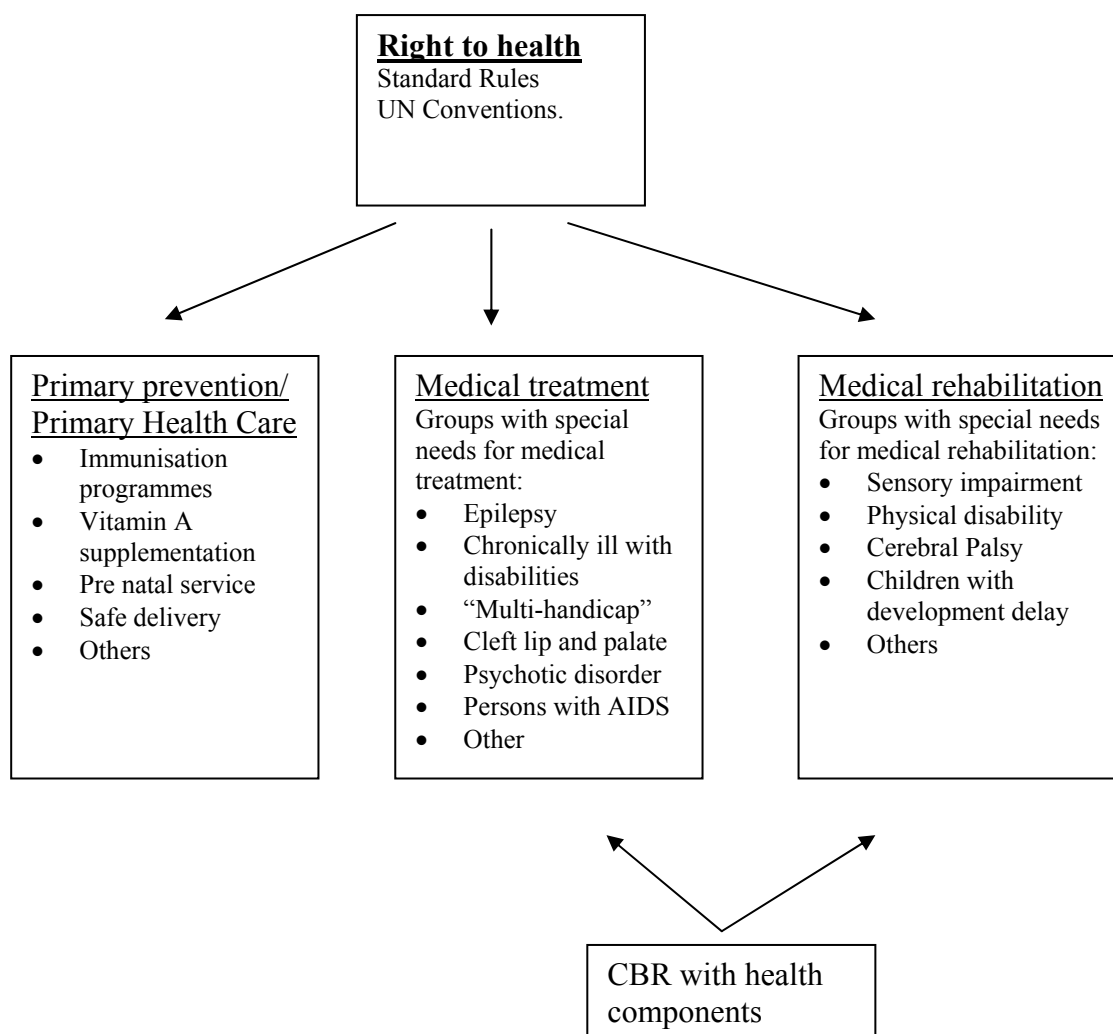
### **5.7. The right to health**

Disability has both a medical and a social dimension. The goal of health interventions should not only be prolonged life, but also to improve the quality of life by expanding the range of activities that can be performed. The focus of the health systems today is shifting from prolonging the life to improving the quality of life, from cure to care.

The WHO defines health as *“a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”* [WHO 2000]. This seems like a very idealistic aim in many countries, the health-situation depends on several financial and social factors.

According to Hellberg and Mäkkelä, the aim of the health interventions should be reformulated as *“a sufficient functional capacity for all to lead a personally and socially full and rich life.”* [Lankinen *et al.* 1994: 468] This aim would fit with the ultimate aim of the CBR program, the full social integration of all people. As an example, a girl with a hearing problem may have problems to get integrated into the school if she will not get a hearing device.

## Health and Persons with Disability- a framework



**Figure 6. Medical aspects of prevention and care with special reference to people with disabilities.**

[Jareg *et al* 2000: 14]

Jareg has developed this model for the Right of persons with disabilities to health.

Health service includes medical care, prevention, rehabilitation and health promotion.

The model states that persons with disabilities have the right to primary health care, to medical treatment and to medical rehabilitation. Medical rehabilitation also includes social service for persons with disabilities.

### 5.7.1. Primary Health Care

Primary health care was introduced by WHO at the Alma Ata declaration in 1978 with the slogan “Health for all by the year 2000”. The intention is that resources for health are evenly distributed and that essential health care is accessible to everyone. Prior to



this, health systems of developing countries were mainly hospital-based and disease-oriented. “The Global Strategy for Health for all by the Year 2000” was adopted by the WHO in 1981.

The Alma Ata declaration §6 defines primary health care as “ *essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination*”. [Lankinen *et al.* 1994: 464]

According to the WHO primary health care includes both prevention (appendix 5) and medical treatment. The following elements should be present:

- Education on prevailing health problems and methods of preventing and controlling them
- Promotion of food supply and proper nutrition
- Adequate supply of safe water and basic sanitation
- Maternal and child health care, including family planning
- Immunisation against the major infectious diseases
- Prevention and control of locally endemic diseases
- Appropriate treatment of common diseases and injuries
- Provision of essential drugs

[WHO 2000]

CBR should not be seen in contradiction to primary health care. CBR includes primary health care but is more focused on the social aspect. The aim of primary health care is health for all while the aim of CBR is the full social integration of all people. Health and social services cannot be separated; the two sectors are tightly linked together.

### **5.7.2. Community participation in health care**

Health should be seen as a total well being, both for the individual and for the community. Providing health services is a responsibility of the Authorities, but the

communities and the people themselves should also take responsibility of their own health. The community should be actively involved in the planning and the implementation of health care services, it should be motivated, equipped and empowered to do so. People in the community should also feel a responsibility for taking part in community organised work and services.

As a minimum standard, community participation requires people's co-operation in the planning of services, in the improvement of the economic and social conditions and the general hygiene of the community and in community health education. People also need to co-operate in developing a consensus in the communal and individual health goals and in preventive health measures. [Lankinen *et al.* 1994: 435]

The CBR program promotes community participation. The definition of CBR state that CBR *"is implemented though the combined efforts of disabled people themselves, their families and communities..."* The people themselves and the local community know the needs of their own community and they can build the services on local culture and resources [WHO *et al.* 1994].

### **5.7.3. Health in Palestine**

Until 1994, the Israelis ran the health service in Palestine. After the establishment of the Palestinian National Authorities, the health service in Palestine was handed over to the Palestinian Authorities. Because of the Intifada and the present political situation, the physical, psychological and social problems are high and the need of health and social services is growing. In spite of this, per capita health expenditures decreased from 124\$ in 1991 to 111\$ in 1997 (all sources). In 1998, the Government Health Insurance System was covering only about 50% of the population.

Since 1995, the Ministry of Health has taken the leadership role in the development of the health sector. "The National Health Plan for the Palestinian People- Objectives and Strategies" was made in 1994 and is the national strategy until year 2002. The focus is on development of public health care.

A research shows that Palestine has a too high proportion of doctors in relation to nurses and an ineffective referral system, an overuse of hospital facilities and an under- use of

public health care facilities. Closure of borders, denial of access of patients to hospitals in Jerusalem, obstacles to migration of health workers to undeserved areas and the splitting up of the Ministry of Health in a Gaza- and a West Bank branch leads to extra cost and inefficiency of the health system.

There are different numbers regarding the access to health care in Palestine. The Palestinian Development Plan 1998-2000 states that 277 villages in the West Bank, 14% of the population do not have access to health facilities at all. The Palestinian household survey (PCBS 1996) states that 90% of the households in the West Bank and all in the Gaza Strip have access to public and private clinics within 5 km and 45% of the households in the West Bank and 74% of the households in Gaza have access to hospitals within 5 km. [Jareg *et al.* 1998: 14-23]

The Palestinian families have many children. Due to information campaigns and modernisation of the society, the use of modern contraceptives is expected to increase and the numbers of children are expected to decrease in the years to come.

	Contraceptive prevalence rate	Total Fertility Rate
Palestinian Territories		6,1
West Bank	50%	5,6
Gaza Strip	34%	6,9

**Table 4:** Contraceptive Prevalence Rate and Total Fertility Rate [PCBS 1999: 32] [Jareg 1998: 14]

The infant mortality rate and the life expectancy at birth are high for both sexes. There is a decreasing mortality from diarrhoea diseases and malnutrition and an increase in mortality from respiratory infections (pneumonia 14,7%) and other causes that originates from pregnancy and childbirth (congenital diseases 15,7% and prematurely born children 13,9 %). The main reason for the mortality of children under the age of 5 is traffic accidents and accidents at home, including poisoning [Aars 1999: 8], [Jareg *et al.* 1998: 15]

Infant Mortality Rate for Male	25/1000
Infant Mortality Rate for Female	27/1000
Life expectancy at birth for Female	71,8 years
Life expectancy at birth for Male	70,21

**Table 5:** Infant Mortality Rate and Life Expectancy [Heiberg *et al.* 1993; 63,69,288]

## **6.0. COMMUNITY BASED REHABILITATION/ CBR**

This study was performed in connection with the initiation of the CBR programme in Salfeet. An introduction to the CBR concept and the CBR program in Palestine in particular is given to get a deeper understanding of the CBR-concept and how it may influence the situation of children with disabilities in Salfeet.

### **6.1.Rehabilitation**

Rehabilitation means, *“to restore a persons dignity and/or legal status”*. The introduction to the Standard rules describes the concept rehabilitation as the process which aims to enable persons with disabilities to reach and maintain their optimal physical, sensory, intellectual and psychiatric and/or functional level and to provide them with the tools needed to change their lives in the direction of being more independent. Habilitation is this process for the person who is born with an impairment. (See appendix 5)

#### **Rehabilitation includes:**

- All interventions and training provided for the person with a disability
- All changes/adaptations in his/her own local physical environment
- All general changes needed in the environment in order to diminish or eliminate barriers for people with disabilities
- Equalisation of opportunities provided as the basis of integration
- Promotion and protection of Human Rights

In some cases there is no clear border between some kind of treatment and rehabilitation. [Helander 1993: 16]

There are different ways of providing rehabilitation services. One of the main questions is where the focus should be; on health, on social integration, or what? Should a program provide very good services to a few or should it provide little services to many? Is it possible to provide good services to many with the use of limited resources?

Worldwide, different models for rehabilitation are used.

1. The institutionalised model is specialised and costly. It reaches few people and in some countries it has been used for “storage” and hiding of people with disabilities.
2. Outreaching services reaches more people with disabilities, but is costly and will still reach just a limited area.
3. Projects run by people with disabilities themselves might be cheap, but will probably also reach just a limited area.
4. CBR is supposed to reach all people in the target area and be cheap.

[NAD 2000]

It might be discussed if the community is in need of specialised services or if it is in need of more community based services and community development. Traditionally, the view has been that it was the impairment and disability alone that caused the handicap. Now, by the introduction of the CBR concept, it is recognised that the greater cause of handicap lies with the possibilities for participation in the family and in the community.

#### **6.1.1. Modern history of rehabilitation**

The traditional system of rehabilitation has its roots from the 19<sup>th</sup> century. Small institutions took care of people with disabilities. The institutions provided food, shelter, education and sometimes also vocational training. After the Second World War, the number of people with disabilities increased a lot in the industrialised countries and to provide people with rehabilitation programmes became a national priority in many countries. At that time the definition of disability was not clear and the concept rehabilitation included services for people with different kind of chronic diseases, victims of accidents, alcoholics, drug abusers and sometimes people released from prison.

As the western social security systems emerged, many countries made the consideration of a rehabilitation programme compulsory for persons applying for pension or other benefit prior to the retirement age. Diagnostic and therapeutic methods were improved and multi-professional teams were set up. The attitude at this time was that people with disabilities were difficult to treat, to train and to educate and had to be taken care of by professionals in institutions. The service was based on a medical model of rehabilitation and led to the development of specialised institutions and hospitals. The rehabilitation

system was formalised, complex and mystified. Many governments were not committed to providing public rehabilitation services and let charitable organisations manage and finance the majority of the rehabilitation sector. This system and view was held until the 1970's. Still the medical, institutional rehabilitation model is common in many countries. [Helander 1993: 4]

## **6.2. What is CBR?**

The CBR programs are supposed to reflect the community in which it is present, and since each community is different, each CBR program should also be different. Ingstad claims, *"The big challenge of today is to try to avoid the unintended and unfortunate consequences of development that Europe experienced. In other words- to see that modern rehabilitative measures build on, and develop further, the resources of the local community in a way that promotes integration and avoids segregation. This is what CBR is all about."* [AIFO 1996: 23]

There are many definitions of CBR and it is recommended that a clearer definition will be developed, that will be accepted and applied by the majority of organisations working with CBR. A clear definition would also make it easier to assess and to evaluate the CBR programs [Jareg *et al.* 1999: 93].

The joint position paper on CBR by ILO, UNRSCO and WHO (1994) is the first international document taking a global look at the CBR approach. A second version of this paper is supposed to be finished by year 2001. The paper has the following definition of CBR: *"Community-based rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services."* [ILO *et al.* 1994]

Jareg states: *"CBR can be understood as all actions in a local community (including those in the family and by people with disabilities themselves), which aim at achieving a better life for people with disabilities. The basic idea is that the persons themselves and the local community have the best opportunity to organise and give assistance in a*

*practical way and know the resources and how to mobilise them. One advantage with this model is that services and assistance developed locally usually build on local culture and resources. The major objectives of CBR are to ensure that persons with disabilities are able to maximise their physical and mental abilities, have access to regular services and opportunities, and achieve full social integration within their communities and societies”* [Jareg *et al.* 2000: 53-54]

Seeing the implementation of the Standard Rules as the ultimate goal to achieve, social inclusion should be in focus of the CBR programs; providing access to resources, to social life and to increased respect and participation.

In the Nicaraguan discussion paper, CBR is defined broadly as a way to reduce the effect of impairment. “*CBR is all ongoing processes favouring rehabilitation and trying to improve the situation of persons with disabilities in the community.*” [Jareg 1989: 9, 38] [Jareg and Ingstad 1991: 1] [Jareg 1991: 4]

The international strategy of CBR started up in some few developing countries as early as in the 1950's, simply because the medical approach to rehabilitation was too expensive. The WHO promoted the idea of community health workers in the 1970's, and in 1976 the WHO formally introduced the concept of CBR. The intention was to provide a more comprehensive approach to rehabilitation, and the understanding of the situation of people with disability grew as rehabilitation workers started to facilitate the social integration of people with disabilities. The early WHO model of CBR had a more medical approach to rehabilitation. The ideology of CBR has gradually changed as the years have gone by; the CBR concept now has a stronger social approach.

In 1989, the WHO developed the CBR manual. The WHO manual provides practical guidelines for all people at all levels involved in a CBR program. The manual has for many years been an effective tool that has promoted CBR in more than 30 countries. After 12 years of using the CBR manual, it might be on time to revise it according to the CBR development. Some limitations of the manual is that it is focused mainly on health and social components, it has little information about community work in general and it is culturally insensitive for some countries. It also has very high expectations to the role of volunteers, and it has often shown that volunteers often have a short-time commitment.

The WHO model also has insufficient coverage of certain types of disabilities. [WHO 1989] [Ingstad 2000]

The early development of CBR started with grassroots organisations in developing countries, often in the NGO-sector. CBR was often initiated by community members and persons with disabilities, and had little support from the health professions. During the last decade, several governments and health professions have been actively involved in the programs. The CBR concept may be adopted both in industrialised- and in “developing” countries. CBR is a comprehensive approach, concerning disability prevention and rehabilitation; it also includes the provision of income generating activities. The program should reach all people with disabilities where they live and the service should be integrated into the existing infrastructure. The major objective is to ensure that persons with disabilities are able to maximise their physical and mental abilities, have access to regular services and opportunities and that they achieve full social integration. CBR is no longer seen as the opposite of specialist services, but it has a broad relationship extending from the community to the specialist health care rehabilitation facility as the program uses the existing referral system.

The CBR process may start at grassroots level and develop relationships with other rehabilitation services through the referral system. CBR often uses simple technology and is said to be cost-effective. The cost effectiveness of CBR programmes has in many cases not yet been documented.

The CBR-program is supposed to focus on Human Rights, it gives special attention the rights of woman and children; promoting the Convention on the Rights of the Child. The girl child is the main priority. [Mendis 1996: 20-21] The program aims to create an acceptance of the Rights of persons with disabilities; to economic, educational, social, cultural and political Rights [Mendis 1996].

The activities at the community-level are focused on empowerment of persons with disabilities and their families, attitude change, model building and mobilisation of community resources.. Empowerment of the communities is also in focus. However, it has been discussed whether some CBR programmes are focusing more on the interventions of the programme than on the empowerment aspect. The interventions are



means to empowerment, and the CBR programs should document which activities that are promoting the process of empowerment of persons with disabilities.

Transferring- and di-mystification of knowledge is claimed to give a long-lasting positive effect. Different fields are involved, for example physiotherapy, awareness rising, income generating activities and vocational training. These are among the reasons why there are many interpretations of CBR [Helander 1993]. At the district- and the national level, the CBR program works with networking, training, research and it works to improve the referral mechanisms. At national level it emphasises developing policies and national planning that will benefit people with disabilities. The CBR program promotes legislation in order to strengthen the rights of people with disabilities.

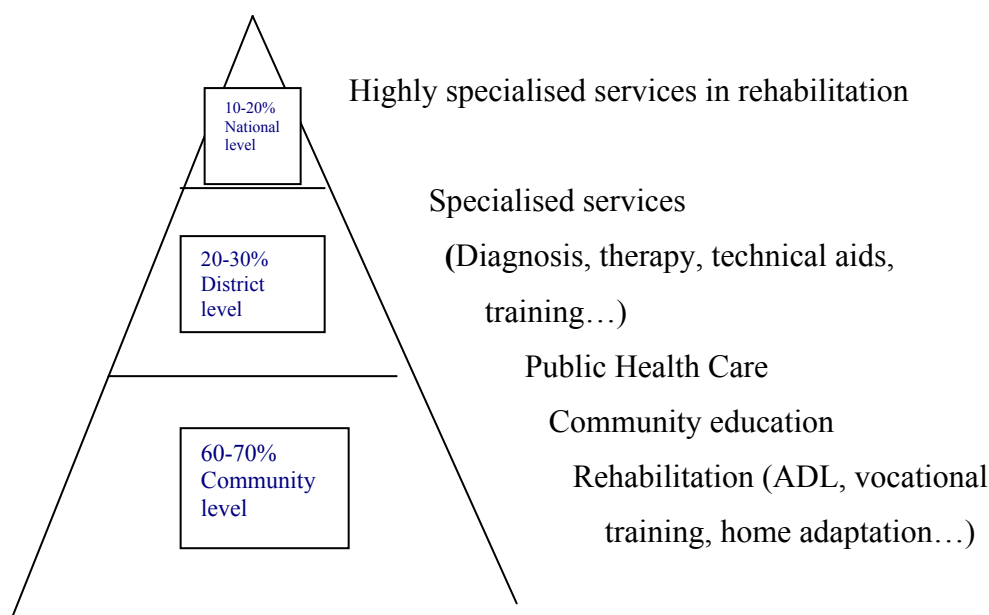
Many CBR-programs are small-scale, supported by NGOs. It might be difficult to expand small-scale programs into a national program. Mobilisation of the community for the transition of small-scale CBR projects to a national program is a critical element for the sustainability of the CBR programs. It is often a problem that the CBR programs are not seen in the large political and economical context of the countries where they are present.

September 1999, a Nordic workshop on disability and health was held in Oslo. The participants agreed that CBR should have the following components:

- Create a positive attitude towards people with disabilities.
- Include education and training opportunities.
- Provide rehabilitation services.
- Provide care facilities.
- Income generating activities.
- Management, monitoring and evaluation.

[Jareg *et al.* 2000: 53-54]

The following model shows that CBR involves the Government, NGOs and private providers; it involves many sectors; health, education, social services, labour and others. CBR addresses different levels; community, district and national. The model describes how services are distributed in a CBR concept. The concept may have a “bottom up” approach, from the community to the national level or it may be introduced from the national level, a “top-down” approach.



**Figure 7: The CBR structure** [Harami 1999]

This study is based on NAD's model of CBR that states that the CBR programs should be built on equal rights and equal opportunities. The ultimate goal is social integration and the strategy is to give a comprehensive approach to rehabilitation, support empowerment of people with disabilities, provide decentralised services, social change and multi/inter-sector co-operation. The stakeholders are people with disabilities, their families and the local communities. The CBR programmes seek to change the knowledge, attitude and practice of people in the community and it promotes self-organisation of people with disabilities and other community member. CBR involves the health and social services, the educational- and labour-sector, as well as other services. The most important tools of a CBR program are the CBR workers at all levels and the WHO manual. [Spadacini 2000]

In order to sustain a national coverage of the programme, NAD co-operates mainly with governmental structures and gives the governments the responsibility for the programmes. Experience shows that in many locations, CBR programmes that are not involving the national governments and are not included in the national plans of the country often remain with limited geographical coverage. However, the CBR programs have not succeeded until they have reached to all levels of society. The reason for working mainly with the authorities is that NAD considers the authorities to be the prime force in accomplishing the improved services for people with disabilities. The authorities have the overall responsibility for people with disabilities in the country, and need to build their competence at all levels. The authorities do represent the network (education,

health etc.) that people with disabilities are to be integrated into. The national authorities are able to co-ordinate the services and promote co-operation among the service-providers both in public and private sector. As long as the national authorities get the responsibility for the programmes, NAD does not have its own administrative structure in the various countries where NAD operates.

According to NAD, the CBR programme is a community development programme. This is also stated in the definition of CBR. The CBR program should lead to the development of a society for all. *“The goal of the CBR project is to promote the social integration of disabled persons into all levels of society based on equal opportunities, Human Rights and equal access to service, i.e. to work towards a democratic society. The target group is all persons with disabilities of all ages, with special reference to females [Bergström 2000: 37-38 ]. Community development is mainly about supporting processes that will have a positive and sustainable effect on a community.” It is important when working in and with a community to build upon what is there already. Identifying resources and processes in the community, for furthering the development of children, is a vital part of child centred community development work” [Jareg 1994: 91].*

There is an ongoing discussion whether or not CBR should be run and controlled exclusively by people with disabilities. NAD holds the opinion that people with disabilities should have influence of the program and matters of importance for themselves and they should have influence through their organisations. On the other hand, people with disabilities should not necessarily hold the management of the program. According to NAD, this would be another form of unwanted segregation of people with disabilities; CBR should involve all people. In the implementation phase of the CBR program it is often useful with a mixture of approaches and people with disabilities should be role models. [NAD 2000]

Mrs. Harami, the Manager of the Jerusalem office of Diakonia holds the opinion that whoever holds the management of the CBR program; people with disabilities and their families are the owners of the program. They should set the priorities, identify the objectives, influence, monitor and evaluate the impact of the project. People with disabilities are the main beneficiaries and should participate in all activities of the project; they are role models and pressure group within the community [Harami 1999].

David Werner holds the opinion that people with disabilities also should hold the management of the CBR program [Werner 1988]. O'Toole supports this statement, holding the opinion that workers with a disability tend to be more sensitive to the needs and feelings of other persons with disabilities and they are more likely to involve persons with disabilities in the problem solving process. Leaders with disabilities are often good role models for other persons with disabilities. A program managed exclusively by people with disabilities needs teaching and back up from professionals. The lack of adequate professional support and referral is one of the biggest obstacles to successful CBR. The involvement of the family as an active participant is important for the success of the program. [O'Toole *et al.* 1995: 18, 22, 106]

Some disadvantages of CBR have been mentioned. Some families state that they do not have the resources to follow up their child and they do not handle to get more responsibility. The lack of specialised training for service providers may result in a dilution of care and services for people with disabilities, and the provision of professional services may be reduced. There may also be difficulties in actualising decentralisation. In some countries a problem has been that the community involvement is not always reliable and there may be a lack of local resources. In other countries the governments have refused to take responsibility for service provision and there may be difficulties in large-scale co-operation and co-ordination. [Peat 1997: 34]

### **6.3.Mainstreaming**

Providing services for persons with disabilities should be a concern both for Governmental institutions and for NGOs. However, many organisations and institutions are not including the disability-aspect into their services.

Mainstreaming is a strategy to integrate services for all people into the ordinary services, instead of building a separates system for people with special needs, like people with disabilities.

*The term mainstreaming in development co-operation in health means that health requirement for people with disabilities should be included in the general services. .*

[Jareg *et al.* 1999: 82]

February 2001, NORAD held a seminar about disability issues and mainstreaming. The assumption made by many organisations present was that in many developing countries, people with disabilities are not included in the mainstream activities. There seems to be little documentation on this issue and it is difficult to get an overview of the situation.

One exception might be Uganda, where the official health policy states that people with disabilities are supposed to benefit from the mainstream services, even get more services because of their special needs. [Jareg *et al.* 1999: 82-83]

The Nordic countries (Norway, Sweden, Denmark and Finland) are all focusing on development programmes aiming to alleviate poverty. The Nordic countries have development programs providing service for people with disabilities, but the mainstream programs do not necessarily include people with disabilities. The Nordic countries also have programmes targeting people with disabilities, but the documentation of the share benefiting people with disabilities is not documented, except for the case of the CBR programmes. [Dyssegaard 2000: 23, 39-40, 50]

There are different strategies of including disability issues into the development co-operation.

1. Inclusion of disability concerns in all aspects of mainstream planning, including sector wide approaches.
2. Disability-specific components in mainstream programmes
3. Disability-specific projects.
4. Intersectoral programmes that aim at mainstreaming people with disabilities. CBR is an example of this, aiming to integrate people with disabilities into the mainstream activities.

#### **6.4. Evaluations of CBR-programs**

Evaluations enable rehabilitation workers in different locations to learn from each other. Before starting up a CBR program, there should be developed a monitoring and evaluation process. Evaluations may focus on the needs of the community and the target population, of the utilisation of services and the quality of care, or of the governance and management functions. An evaluation may focus on the financial, physical or human resources or the relevance, the impact, effectiveness and output of the programme. An evaluation is needed to assess whether the programme has had an impact on the target population, it will determine the progress of the programme and one may make adjustment in order to improve it. An evaluation should measure the effectiveness of the CBR-programme participants; the cost-effectiveness and it should assess the sustainability of the program. It should further assess if the program is consistent with established policy and is influencing the development of related policy issues and it will determine if the programme can be replicated or extended. [Peat 1997: 90]

There is a need to develop a common understanding of all aspects of CBR and to evaluate all these aspects. Quantitative indicators such as prevalence rates and coverage of services are easiest to measure, while qualitative indicators, such as changes in the quality of life and the efficacy of interventions are difficult to measure. [O'Toole *et al.* 1995; 251] WHO Disability and Rehabilitation Team set some program priorities for 1999-2000, where impact assessments of CBR was one of the priorities, requested by the UN Special Rapporteur [Jareg *et al.* 2000: annex 3].

Most of the CBR evaluations are unpublished and difficult to access. R. Jaffer points out the need to develop a system to monitor evaluations. There is also a need to develop indicators to assist evaluators in what constitutes CBR [Finkenflügel 1999; 51-64, 89-94]. The Hässelby seminar also stated that there is a need to develop a common understanding of all aspects of CBR and to evaluate all these aspects [Bergström 2000]

WHO and SHIA are planning to do a global evaluation, to examine the impact of the CBR strategies on the living conditions of people with disabilities. The objectives is to review the involvement of persons with disabilities and their families in CBR programmes, to examine the change in living conditions of persons with disabilities after

the implementation of the CBR programme and to identify the most helpful strategies for improving the living conditions of people with disabilities. The evaluations will use a participatory research approach, both providing qualitative and quantitative indicators.

In 1996, AIFO held a workshop on CBR and country experiences of CBR. General advises were given and country experiences were shared. O'Toole raised some basic issues: How can the CBR-philosophy be translated into practice and for whom is the CBR-approach meaningful? *“Do parents welcome a teaching or training role with their children? Is community involvement in the area of rehabilitation realistic? Are there people in the rural villages that would wish to offer their services in such a program? Is it possible to develop rehabilitation as a process, in which a number of people are involved, rather than as a product which is dispensed at the local level?”* [AIFO 1996: 99]

A list of evaluations of CBR identified by the researcher follows. The list is not comprehensive, but it provides many useful country experiences of CBR.

Country	References (see the reference list, appendix 6 )
Afghanistan	Gautron and Jarrarr 1996
Botswana	Ingstad 1997
Cape Verde	Ministry of health and social promotion off Cape Verde 1997
Ethiopia	Rädda Barnen 1997
Eritrea	Sium et al. 1998
Ghana	O'Toole 1996
Guyana	AIFO, 1996 (O'Toole). O'Toole 1990
Indonesia	O'Toole 1998
Jamaica	Bischoff et el.1996
Mauritania	AIFO 1996 (Camara)
Mongolia	AIFO 1996 (Carraro)
Nicaragua	Jareg 1989, Jareg and Ingstad 1990, Jareg 1991, Jareg 1994
Phillipines	AIFO 1990
Uganda	O'Toole 1996, Kayonga et al. 2000
Vietnam	Bjork 1998, Hanh 1997, Hai 1997, Rädda Barnen 1997, Lopés 1995, Sharma 1999
Zimbabwe	AIFO 1990
Yemen	Ministry of Health and Social Promotion of Cape Verde 1997, Nelke 1999, Brouillette et al. 1997

**Table 6: Evaluations of CBR-programmes** [Student A.J.Retterholt 2000]

Experiences from Botswana shows that 27% of the persons with disabilities felt their social life had improved after the introduction of CBR. 32% felt improved skills in

activities of daily living, 27% felt better physical functioning, 29% felt improved communication and 25% felt improved mental functioning. It is pointed out that it is difficult to make a distinction between the improvement caused by natural development, the improvement caused by one's own initiative and the improvements caused by inputs from the CBR program. [Ingstad 1997: 152] Several mistakes have been reported; the program started too large and was difficult to manage. The program overestimated the manpower available for rehabilitation and there were not enough trainings given initially to the medium level workers. The program should reach all levels, but it did not involve the clinic staff nurses from the beginning. Insufficient emphasis was placed on community mobilisation and participation. An additional problem was that a competing CBR program started up by another NGO. [Ingstad 2000]

In Nicaragua, a discussion paper trying to identify ongoing positive processes and "good examples" in the community regarding children with disabilities was made. This has some similarities to the study performed in Salfeet. The evaluator visited pre-schools and schools, social services, health institution, parent groups, associations of people with disabilities, homes of children with disabilities as well as Ministries, Governmental organisations and NGOs. The evaluation states that integration in pre-school is much easier than integration into school; the integration-process should therefore be done in the right order. The high unemployment-rate in Nicaragua made it difficult to integrate people with disabilities into working-places without special concessions. [Jareg 1989]

Evaluations of CBR-programs in the Philippines and Zimbabwe show a significant improvement in the degree of socialisation before and after CBR. The severity of the disability was much less after the implementation of the CBR program [AIFO 1990: 44].

The CBR Project in Uganda started up in 1992 and is said to be very successful. An evaluation shows that 83% out of 172 persons with disabilities interviewed felt the program had been to great help. Positive effects mentioned were: new teaching ideas, help with income generation schemes, better access to medical, educational and vocational rehabilitation facilities and more support from their families. The responses from their family members were just as positive. The family members mentioned positive effect on the person with disabilities like improved ability, better integration into the society, more confidence, improved communication and involvement in income



generating activities. Only 12 out of 164 family members reported “no change”. The 4 days training program for persons with disabilities and their families was well functioning. The Uganda programme emphasised the importance of multi-sectoral approach, but the evaluation mentions that the collaboration with organisations of persons with disabilities could be improved. The CBR program in Uganda has included many children in school, especially children with movement problems. Still, more assistance is needed to widen the group of children with disabilities benefiting from integrated education. The program provided good technical aids, locally made. The evaluation is concluding that the program is strong at grass roots-level but there is a need to develop a stronger national identity for the program. [O’Toole 1996]

The Nordic Consulting Group reviewed the CBR programme in Uganda, year 2000. The evaluation states that the CBR program has made an important achievement regarding empowering people with disabilities to realise their rights and get appropriate service delivery at all levels. The main criticism is that the CBR programme has a low coverage of the target group, which makes it necessary to adjust the approach. The multi-sectorial co-operation is also inadequate and the involvement of the private sector in the program is still limited. [Kayonga *et al.* 2000: 5]

The CBR program in Ghana started up in 1992. The evaluation of the programme was not so good, and it led to a total reorganisation of the programme. The lack of multi-sectoral collaboration was among the main problems identified. The management of the CBR programme needed more training in all aspects of CBR, the staff had to co-operate and learn from other CBR programs and participate in overseas conferences. The evaluation point out the importance of letting the local management take the responsibility of the program. The UN agencies and the CBR Advisory committee needed to take a more serving role and let the Ghana CBR Management Team take the lead. The needs of people with disabilities should be in focus rather than ensuring the political correctness of the program. After the evaluation in Ghana, a national CBR conference was held. The conference concluded that more information about the program and about CBR in general had to be available to the public. The schoolteachers felt a need of better preparation before including the children with disabilities into the school, and the CBR agents felt a need for more training in order to examine which technical aids that should be recommended to the persons with disabilities. (It may be discussed whether this is a job

for the CBR workers; according to the official CBR approach should the referral system be used for this). As a result of the evaluation, income generating activities and a credit rotation fund started up to help out the financial situation of the families with disabilities. [O'Toole 1996]

The CBR program in Guyana started up in 1986. Experiences show that *“CBR has demonstrated what can be achieved, at low cost; creating not only better opportunities for people with disabilities, but a sense of hope on the part of families that they can play a significant role in the development process. Communities have become more aware of disabled people in their midst and, at times, have played a major role in planning ways to meet their needs”* [AIFO 1996: 46, 66]

CBR was initiated in Mauritania in 1989. The CBR program has been successful in involving the people with disabilities in national organisations and community attitudes towards the CBR program have changed from sceptical to supportive. However, the program has also faced some difficulties. The co-operation between AIFO and the Government has not been satisfactory, because of lack of a clear policy. There have also been a lack of political support and also lack of a national plan. Another problem has been that the training of rehabilitation workers has not been good and there has been insufficient funding to support the strengthening of the program. The CBR program in Mauritania has experienced that the evaluation techniques were inadequate. [AIFO 1996: 78-80]

In Mongolia, the CBR program started up in 1992, and it is now a national program. The program has two distinct approaches to CBR; in the urban areas the CBR program has a classical approach, involving the communities. 65% of the population are living in the rural areas with very low population-density- where small groups of persons, often part of one extended family live together. In this setting, the CBR program involves the family and not the whole community. One issue raised is if it is right to give more responsibilities to parents and family members, especially when these people are already living in extremely poor conditions. According to the Mongolian CBR program, the role of the referral service in supporting the parents and the family is very important. The Mongolian CBR-program sees CBR as a complementary program to the institutional rehabilitation model, not an additional program or an alternative. [AIFO 1996: 96-99]

A CBR-workshop was held at AIFO, Bologna in 1998, concerning “*Participatory research Methodologies for understanding the issues facing CBR programmes*” The workshop focused on the need for systems thinking; to look at the organisation as a whole instead of looking into separate parts. Since the causes and the effects are complex and have a long time gap between them, it is difficult to identify the correct reasons or the solutions. The workshop identified some major issues facing CBR programs:

- Lack of access and inclusion of children with moving difficulties in the mainstream primary schools.
- High dropout-rate of volunteer CBR workers in the CBR programs.
- The provision of mobility assistive devices like callipers and crutches for young children and adolescents are often insufficient.
- Low level of community participation in the CBR-program.
- Lack of governmental commitment to CBR-programs.
- Lack of data about persons with disabilities. [AIFO 1998]

The CBR program in Eritrea started up in 1994. People with disabilities confirm that the program has been helpful, they experience improved health through referrals to medical treatment, better access to schools, positive changes in the community attitudes, improved social integration, more job opportunities and increased access to the shared income in the communities. The program is said to be quite cost effective and sustainable, but it lacks documentation and reports. Villages not included in the programme have observed the changes in the villages with a CBR program and push for inclusion in the program. Still, some goals have not yet been fully reached; there is a need for a further development of special needs education, medical rehabilitation, vocational training and income generating activities. The evaluators recommend providing more training of staff at different levels. The local CBR workers must get better methods to introduce themselves to the communities in order to make their role and functions clearer and the documentation and reporting system have to be improved. Expansion of social services and further community development is also needed and persons with disabilities have to organise themselves better. [Sium et al. 1998]

At the Nordic Workshop on disability and health in Oslo, Norway (1999), some experiences related to CBR were shared.

- CBR may be interpreted as an easy and cheap tool to provide medical rehabilitation. If the Ministry of Health is implementing the CBR-program, the social aspect may disappear.
- A program in Central America faced a general political uneasiness in the Government to mobilise communities. The local Ministry of Health wanted to keep CBR as a health project based in the Ministry, and did not want to include the social sector.
- It might be better to organise the national CBR-programs under the Ministry of Social Affairs rather than under the Ministry of Health. On the other hand this makes it more difficult to receive donor funds, as a sector wide approach usually does not exist in relation to the Ministries of Social Affairs.
- In Mozambique, there was a tendency to centralisation of the CBR projects. The CBR programmes are supposed to build on ongoing processes in the community, but here it was the only organised activity in the community.
- In general, people working in the central areas do not always understand what it means to include people with disabilities in their work in the rural areas, and do not promote the implementation of CBR there. On the other hand, people at the grass-root level do not always understand the actions of centre-based organisations.
- The volunteers often lack motivation and have a short time involvement in the program.
- CBR is a difficult concept to understand and introduce over a short period of time.
- Rädda Barnen (Save the Children, Sweden) works to include children with disabilities in all programs that are dealing with children, instead of developing segregated programs for children with disabilities.
- Persons with sensory disabilities are afraid not to be prioritised. The blind persons need assurance of the quality of the education, and the teachers need training in special education.
- The professional do not always understand the usefulness of involving persons with disabilities in the planning and the implementation of CBR.

[Jareg *et al.* 2000: 54-56]

The experiences indicate that not all CBR programmes have been successful and that it takes time to understand and to implement them. To make a national, decentralised programme is difficult in many countries; its success is often dependent on the level of decentralisation prior to the introduction of the CBR program, and on the involvement of people with disabilities in the programme. The early WHO model is focusing on the use of volunteers, while experience shows that the volunteers often have a short time commitment and that there is a need for local employees. Since the CBR programmes are focusing on people with all kind of disabilities, some groups may feel that their needs are not met. The CBR programmes are difficult in each culture, and the challenges faced vary according to the expectations faced, and the experiences gained.

### **6.5. The Palestinian CBR program**

In Palestine, a biomedical approach to rehabilitation has traditionally been the trend. Persons with disabilities have stayed for a long time in institutions and physiotherapy has been the main rehabilitation service. The services have been poorly co-ordinated and planned for, being overlapping, inaccessible, unaffordable, urban-based and disintegrated and less than 10 % of persons with disabilities received any service. Persons with a disability have been at the receiving end and not actively involved in developing the services.

A CBR conference was held in Palestine in 1990. This resulted in the implementation of the CBR program, a co-operation between Diakonia and NAD in Gaza the same year. Diakonia and NAD already had several years of experience in the area. The intention was to strengthen and co-ordinate already existing projects. At this time, 17 Palestinian NGOs were brought together and developed a plan for implementing the program. The fact that all these organisations have managed to create a common understanding and a common strategy is maybe the main reason for the success of the Palestinian CBR programme.

The objectives of the Palestinian CBR programme are:

#### **Development objective**

*“The Palestine CBR program aims at improving the quality of life of disabled persons within the context of overall community development and by equalisation of opportunities*

*for disabled people which is based on equal rights concept, the ultimate goal of which is to achieve full social integration “*

Specific objective

- *Improve quality of life of disabled persons and increase their self-reliance for independent living.*
- *Enhance equal opportunities for disabled persons.*
- *Promote mainstreaming of rehabilitation into all sectors.*
- *Improve the level of quality and accessibility of rehabilitation services.*
- *Provide support for disabled people organisations.*

[Diakonia *et al.* 2000] (appendix 6)

The CBR program in Palestine is not intending to be a service deliverer, but “a spider in the net”, facilitating and mobilising resources in the community. The strategy is to support the NGO sector, support the co-ordination between NGOs and between NGOs and the government. Capacity building of the Central National Committee of Rehabilitation is a major developmental strategy utilised. Culture, like a puppet festival, have been utilised to change the negative attitudes towards people with disabilities. The CBR program in Palestine co-operates with the CBR programs in Jordan and it co-operates with other international organisations. [Diakonia *et al.* 2000: 1-4]

The CBR program has been implemented as 4 regional programs; Gaza (1990), Northern (1991), Central (1993) and South (1994). [Diakonia *et al. Half year report* 2000: 1] It is covering an area with more than 244 local communities, where about half of the population in the Palestinian Territories (1,3 millions) are living. A total of 28502 persons with disabilities have been included in the program; 5588 persons are still active in the rehabilitation process. 2964 children have been integrated into schools and kindergarten and 766 persons have been integrated into work places as a result of the CBR program. In 1999, 106 persons were employed at the rehabilitation program. [Spadacini 2000: 3]

An evaluation performed by Nobel states that the Palestinian CBR programme is working to develop democracy and Human Rights in Palestine. In 1997, about 20 Palestinian NGOs were working on Human Rights issues, and in addition there were about a dozen having Human Rights aspects in their program. [Nobel *et al.* 1997: 35-37]

Diakonia and NAD state, *“The program supports the Human Rights of disabled persons in a broad sense; to equal opportunities, to social integration and to have access to community services and resources. The program targets disabled persons themselves, supports their rights to association and promotes their active participation in building a society for all.”* [Diakonia 1999: 7]

#### **6.5.1. Organisation and administration of the CBR program**

Partners in the program are both at the national level, including national bodies and specialised institutions, at intermediate level and at community level, including 17 NGOs as well as it involves the private sector (appendix 6). After the Palestinian National Authorities took office in 1995 the Ministry of Health, the Ministry of Social Affairs and the Ministry of Education have been actively involved in the program. In the beginning there was quite a bit of tension between the Ministries and the NGOs but this seems to have developed positively.

Diakonia is a Swedish church-based NGO and NAD is a Norwegian independent NGO, supporting programs for people with disabilities in Norway and in several other countries. These organisations are not the implementing agencies, but are providing money and technical support to the program.

The financial support of the program is approximately 50/50 from Diakonia/ SIDA and NAD/NORAD (NAD contributes to 20% and NORAD contributes to 80% of the Norwegian funding). Year 2000, the Palestinian CBR program had a total budget of about 15 mill. Norwegian crowns. Notable is that for every dollar invested through external resources, the local communities add in average more than three dollars. [Diakonia 1999: 19]

The Central National Committee of Rehabilitation and the Red Crescent Society are the co-ordinating and implementing bodies at national level. Each region has a regional committee and a regional project Manager. 2-3 intermediate level supervisors assist the project Manager. [Diakonia *et al.* 2000: 1]

The present agreement between NAD and the CBR-program ends by year 2001, but NAD assumes that the co-operation will continue in one form or another also after this period. The rehabilitation program will probably be run by NGOs in the years to come and the

work with creating political acceptance for the program will continue. The plan of the CBR-program is to cover 70% of the population by year 2001. However, more important than covering a certain area with the program is to reach the ultimate aim: the development of a national rehabilitation program in the country. [Diakonia *et al.* 2000: 5-9]

### **6.5.2. CBR in Nablus**



**Figure 8: CBR workers from Nablus doing a house- to house survey in Derlokson. September 2000**

(Photo: Anne Johanne Retterholt)

Nablus is the centre of the Northern CBR program that started up in 1995. The Northern area has 600000 people and the program is continuously expanding in order to reach the large population. The program is run- and owned by Union of Medical Relief Committees and the Red Crescent Society in Nablus, that hold the management and the infrastructure of the program. The CBR project organisation consists of the regional- and the local Manager, an assistant Manager and 12 rehabilitation workers. The rehabilitation workers have a 6-week course in rehabilitation and they are using the WHO manual as a tool.

Some of the results accomplished by June-2000 were:

- An area with 70000 people has been surveyed. The objective is to cover an area with 150000 people with program activities.
- 3063 persons with disabilities are involved in the program.



- During 1999, 6634 home visits have been organised for persons with disabilities currently enrolled in the program.
- 104 children with disabilities have been integrated into normal schools and kindergartens during year 1999. The total number of children with disabilities integrated at school is 629.
- 36 persons with disabilities have received vocational training and got a job by 1999.
- 516 volunteers from different communities are participating in program activities.

[Diakonia *et al.* 2000]

### **6.5.3. CBR in Salfeet**

The CBR program in Salfeet is a part of the Northern CBR program, administered from Nablus. 24/4- 19/5 2000, 7 CBR workers performed a house-to-house survey of the area. The team visited 1246 houses and identified 3% of the population (210 persons) with a disability; 20 of them had multiple disabilities. Also here it might be assumed that the number of people with disability has to be higher (according to the WHO; at least 6-7%).

After the survey there were an evaluation-period before the CBR worker started working in the village August 2000. The CBR worker is supposed to visit Salfeet every day, 6 days a week in the time to come. The CBR worker is not planning to withdraw from the area in the future but to reduce the time and resources spent in the city as the program develops.

The first step of the program is to help people with hearing-difficulties to have a comprehensive control by a specialist. There is an agreement between the Red Crescent Society and the CBR program to refer all people with hearing problems for an audiology test. There has also been established an agreement with Nablus Speech Therapy Centre for co-operation.

The CBR program in Nablus is planning to design a comprehensive program for early detection and early intervention in schools and kindergartens in Salfeet. The CBR program in Salfeet will follow the guidelines described in this chapter of this thesis.

#### **6.5.4. Reports and evaluations of the Palestinian CBR-program**

In 1993, CBR-news had an article about the CBR program in the Occupied Territories. It gives a description of the program at the start. The program is assessing needs in the community. The program aimed at problem-solving, social integration of people with a disability, prevention of disabilities, awareness rising and promotion of positive attitudes. The CBR-program tried to make use of skills and resources in the community and to empower and mobilise people with disabilities so that they may run the program themselves one day. The vision at that time was *“That people with disabilities will be empowered and raise their voices on day to demand their rights, take full charge of their lives as equal members of the community and design their own programmes”*. [Harami 1993: 5]

In 1994, the Swedish newspaper “Svenska Dagbladet” had an article about the Palestinian CBR-program, concluding that the program is a school of democracy. The democracy is dependent on the situation of the weakest members of the community, women, children and the persons with disabilities. [Edvardson 1994]

Mendis evaluated parts of the program in 1996, concluding *“In terms of the desired goal of promotion and fulfilment’s of the rights it has developed further than any other program known to the evaluator”* The evaluation gave the Rehabilitation program very positive feedback, but it did not specify clearly what were the positive effects of the program. However, some recommendations were given.

- A significant achievement of the program has been that many children have been admitted to schools at the West Bank. A problem is that the teachers have not had any formal education on meeting their special needs. If this will not be improved, some children with disabilities may drop out of school.
- The role of the community workers should be reviewed.
- There is a need for a comprehensive study of the effectiveness and the impact of the program.
- The capacity and managerial capabilities of the local rehabilitation committees should be analysed and if needed improved.
- The WHO Manual should be revised. The guide for “Local Supervisors” and the “Guide for Local Committees” are no longer relevant to the program.

- There is a need for upgrading-courses for the national trainers.
- A formal Palestinian Sign Language is being developed by another resource and the CBR-program should link up with this resource.
- A weakness with the program is that there are few institutions at intermediate level that are being utilised for referral. The CBR-program has mostly been operating at community level and at tertiary level. Referrals are mainly medical, medical specialities, surgery, specialised therapy and technical aids. By using the intermediate level referral resources, program efficiency will increase. [Mendis 1996: 2]

In 1997, Nobel and Kahsai evaluated SIDA's support to democracy and Human Right at the West Bank and Gaza in the period 1993-96. The report is not a total evaluation of the program, it is evaluating only the Human Rights issues. Democracy is a Human Right and an important tool for keeping the peace. Since the start of the CBR program, there has shown to be a need for a holistic view on how to develop democracy and Human Rights in Palestine. At the starting point the program was focused at emergency aid, but soon it started to develop development-programs that has supported the development of Democracy in Palestine. Diakonia is now intensifying the co-operation with the local communities and the NGOs, the organisation tries to co-ordinate and develop a broad definition of democracy and Human Rights. Conflict-solving and non-violent methods at all levels of society, information and co-operation with women-groups should be in focus. The growing co-operation between the Israeli and the Palestinian NGOs is a very positive effect of the CBR programme.[Nobel *et al.* 1997: 3, 29, 72-73]

In 1997, the CBR program was also analysed regarding its cost-efficiency. The program was found to be quite cost-effective and sustainable from a cost-efficiency point of view. At the Northern CBR programme, direct costs of the programme was about 1 US\$ per capita. The CBR programme has been very successful in mobilising community resources. 1 invested US\$ yielded 1,5 US\$ in community contributions to the CBR programme. The political situation in Palestine is expected to influence the possibilities of the Palestinian CBR programme to develop. Many people involved in the CBR programme at the time of the evaluation, lacked vision about a positive political development and were worried about the future.

It is mentioned that the positive policy and attitude of the Palestinian National Authorities towards the CBR programme is an important factor regarding the success of the program.

Some critical remarks were added to the in general positive evaluation. It was found that many people consider that the CBR program suffers from low quality services and training courses due to inefficient quality controls. Probably this is due to a misunderstanding about the CBR concept; the CBR workers are not supposed to be service deliverers but facilitate the appropriate service delivery by using the referral system. Palestine has many NGOs providing free of charge service and this has triggered a shopping mentality and expectation climate leading to high demands on NGOs.

Another problem faced was that almost all the CBR workers spoken to had problems defining their own roles in the programme. The CBR workers themselves did not see clearly the difference between being a service deliverer and being a service facilitator.

The inclusive education programmes were also criticised. The schools found it difficult to include children with disabilities when no additional resources are provided. Many children with disabilities found themselves in the mainstream schools without any special attention given to them. Because of this, many people consider special schools a better alternative if more resources are not added by the Palestinian National Authorities. [Häggström 1997: 32-34]

The Hässelby-Seminar states that *“The Community Based Rehabilitation Programme on the West Bank and Gaza strip is said to be one of the best by which a lot of children have been included in the school system”* [Bergström 2000: 45]

Diakonia states, *“In this project people with disabilities were integrated as a natural part of the community. Successful integration may have been facilitated by years of sharing the common burden of surviving and living during armed conflicts, when all persons could potentially suffer injuries causing disability”* [Jareg et al. 2000: 56]

There is a need of a new comprehensive evaluation of the Palestinian CBR program. An impact assessment is being performed March-May 2001 (SINTEF UNIMED, Oslo) where the impact of the CBR program are planned to be measured on different levels.

The assessment will assess the impact of the program on individual persons with disabilities, on their families and on the communities. The study will use the baseline assessment questionnaire and case-files of the CBR-program, interviews with persons with disabilities and their families and focus group discussions. [Diakonia 2001]

## **Part 2: THE FIELDWORK**

This part of the thesis is based on the results of the fieldwork in Salford and describes the possibilities of children with disabilities in Salford for participation in the family and in the community. The main findings are extracted and illustrated with some selected examples. The research question is wide, including most aspects of the life of the child. This qualitative study will aim to describe some elements of the situation of the people interviewed but the reader must take into consideration the limited time allocated for the research.

### **7.0. THE RIGHT TO PARTICIPATE**

The International Year of Disabled Persons (1981), the World programme of action concerning person with disabilities (1982), and the UN decade of Disabled Persons (1983-1992) all emphasised the right of persons with disabilities to achieve equal opportunities in the society.

Article 23 in the Convention of the Rights of the Child is the basis right for children with disabilities that this research is developed from. Children with disabilities should be active participants in the community and achieve the fullest possible social integration.

The WHO defines integration as “*to be a full member of society, on equal terms, but with ample consideration taken to special needs*”. Integration has to do with overcoming stigma by providing equal opportunities. Integration must be physical possible and it also has to do with the attitudes and the organisation of the responsibilities in the community. Integration means that all members of society should join in the mainstream of community life. Segregation is a vicious circle, when people with disabilities are not participating, when they are out of sight, nobody will get to know them and the feeling of insecurity, the fear and the anxiety for meeting the people with disabilities will often grow.

Normalisation is “*that the various sectors of society should take full responsibility for the needs of disabled people*” This points out the responsibility of all regarding the participation and the integration of people with disabilities. [Ingstad 2000]

Even in poorer and in developing countries the focus have shifted from institutionalisation to family and community care. The society has to recognise that all people have equal worth and equal rights and all people should share the opportunities and means needed for self-actualisation.

One needs to understand all aspects of the culture in order to understand the needs, the resources and how the people really are treated. The felt needs are not always the needs expressed. There may be many reasons why people do not chose to express all the felt needs, like social stigma, taboo, shame, honour etc. One should also understand the social structures, the cultural tradition, the organisation and the lines of authority prevailing in the community.

The Hanaholm Resolution recommends that; *“disability-oriented development programs should be aimed at enhancing equality, full participation and equal opportunity for disabled persons and at the same time focus in particular on the situation of disabled women.”* [Bergström 2000: 5] This corresponds to the objectives of the CBR program.

Often it is said that the situation of child with a disability is the result of the attitudes of the family or of people in the community (ex. the report: “It’s a matter of attitudes”, Bergström 2000). The following model shows that the attitudes are just one part of a more complex picture, where the situation of children is influenced by many factors. The reason for not integrating the child into the family might be the attitudes in the community. Or the other way around: the reason for not integrating the child into the community may be lack of co-operation from the family’s side.

There is continuously an interaction between the child, the family and the community. The participation of the child depends on both structural and medical conditions. If the physical environment is not adapted (see no. 9.1.) or if the medical condition is very difficult, the participation of the child may be limited or not possible at all.

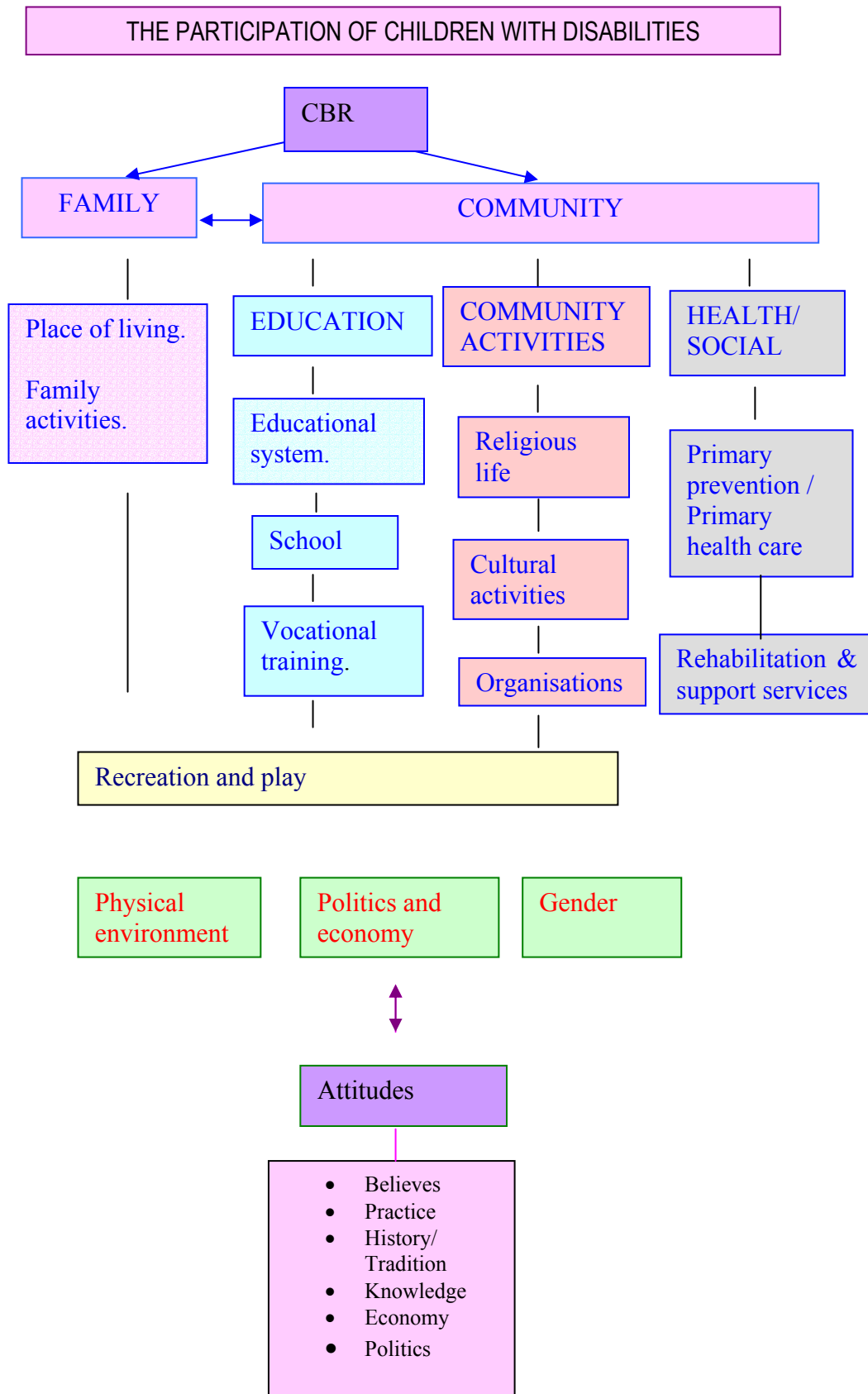


Figure 9: The participation of a child with a disability

[Anne Johanne Retterholt 2000]



The model is developed from Figure 1 of this thesis, illustrating the aim and the objectives of the study. It illustrates different factors influencing the possibilities of participation of children with disabilities.

Both cultural and socio-economic factors influence how the individual and the family cope with the disability. The life situation depends on ethno- medical beliefs, attitudes and behaviour towards the person with a disability and his/her family, the person's experiences and the individual character of the persons. The quality of life varies for all persons, but for the person with disability the situation is more complex. The CBR-structure is influencing all these ongoing processes in society . [Ingstad 1997: 53]

Lack of knowledge and tradition, believes and practices in the society are often the main obstacles for integration. Awareness raising will usually reduce fear and insecurity and promote integration. The political and the economical situation of the family and the community is another important factor regarding having a disability and having possibilities for participation. Being poor make people more vulnerable to disability. Often disability makes the living conditions even more difficult. The influence of the poor in the society is often low and the access to education and information may be very limited.

## **8.0. PARTICIPATION IN THE FAMILY**

The Convention on the Rights of the Child gives a very broad definition of family. Article 5 defines the family as “*parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child...*” (appendix 11) In a Palestinian context, family would mean parents, siblings and the extended family.

The underlying attitude of all Rights and Rules regarding the participation of the child is that under normal conditions, the best interest of the child is to be with and to live with it's family. The Declaration on Human Rights, article 16.3, the preamble to the Convention on the Rights of the Child and the International Covenant on Civil and Political Rights, article 23.1 all state that the family is the fundamental group of society and it is the natural environment for the growth and well being of children. The child should grow up in a family environment with happiness, love and understanding. The family should be protected and assisted so that it can assume its responsibilities in the community.

The Convention on the Rights of the Child article 7.1. and article 9, the Standard Rules, rule 9 and the Law of the Rights of the Disabled in Palestine article 10, all state the right of the child to participate in the family.

The Convention on the Rights of the Child states that the child shall not be separated from his/her parents against his/her will unless it is necessary for the best interest of the child. According to UNICEF, the statement “against his/her will” is not talking about the will of the child alone, it refers either to the parent's will or to the parent's and the child's will together. The child depends on his/her family, the community and the authorities of the society.

The Convention on the Rights of the Child affirms the right of the child to maintain relations and contact with both of the parents. The basis for this right is enshrined in the 1959 Declaration of the Rights of the Child; principle 6 (UN 1959) “ *The child, for the full and harmonious development of his personality, needs love and understanding. He*

*shall, whenever possible, grow up in the care and under the responsibility of his parents... ” [UNICEF 1998: 621]*

The disability of the child will affect the whole family. It is important to identify the situation of the family as a whole, not only the situation of the individual. Both needs and resources of the child may spread to the rest of the family. An example given by many of the informants is that the practical problems, financial difficulties and social stigma are problems faced by the whole family.

### **8.1. The family in Salfeet**

The Palestinians have traditionally lived with their extended family. Some places they still do, but in most cases the families live in separate flats close to their relatives. The Palestinian society is family-centred and also today the extended family and the relatives are great resources to build on.

The families in Salfeet have many children, usually between 5 and 10. As Muslims, the men are allowed to have 4 wives, but nowadays few men have more than one wife. The researcher did not meet any families with more than two wives. The children of the first wife often call the second wife “aunt”. As girls get more education and get empowered, this tradition seems to weaken.

Early marriages and marriages between relatives may cause disabilities. Still, this tradition takes place all over the Palestinian Territories, based on history, culture, economy and religion. At the West Bank, 27 % and in Gaza 31,6 % of the marriages are marriages between cousins. [Holan 1999: 5]

In the Palestinian Territories, the Jordanian law adopted in the 1950’s states that young people might get married when they are 14 years and 6 months old. Even it is allowed to get married at this age, Palestinian girls at the West Bank usually do not get married until the age of 16 and the boys normally get married at the age of 18-20, which is also the case in Salfeet. The traditions and the economy of the family are often the main reasons for early marriage. To poor families with many children, it is a way of trying to provide a safe future for their children and to solve the financial problems of the family.

Some girls are forced to get married early while others chose it themselves. Some teenage-girls dream about getting married and they do not necessarily understand all the adult responsibilities of it. It may also happen that also young boys are forced to get married early, because of the economical situation of the family.

The religious leaders accept early marriages, at least if the girl is 15 or 16 years old, it is a very strong tradition and the religious leaders do not want to work against it. To marry a relative is however not preferred because it can cause disabilities and social problems. In the Hadith, the book of the tradition in Islam, Mohammed said that it is better not to marry a relative, and the orators of the mosque in Salfeet give speeches about this matter.

If cousins are to be married they have to make a blood test six months prior to the wedding, screening for the disease thalassemia. If the test is negative, the couple may get married. There seems to be a misunderstanding about this test, many people think that if this test is negative they will not get children with disabilities at all. Several couples told that the blood test was negative so themselves being cousins could not be the cause of the disability of their child. A medical doctor holds the opinion that these expressions about the blood test are just an excuse to justify the relative's marriage, but the impression of the researcher is that people really do not understand the real danger of marriage between relatives, and they do not understand the limitations of the thalassemia-test.

The Manager of the Public Health Centre is working hard in order to avoid early marriages and marriages between relatives. At the Public Health Centre the girls are encouraged to study and not to get married until the age of 18.

## **8.2. The family with a disability**

The expression "a family with a disability" is reflecting the view that the disability of the child will affect the whole family. The life condition of the family, the attitudes towards the family, the possibilities of the family to participate in social gatherings and community activities etc. will be influenced by the situation of the child.

It is said that children with disabilities often come from poor families. The impression of the researcher is that the children with disabilities in Salfeet come from all parts of society. Most people in Salfeet belong to the middle-class and this seemed also to be the case for the families with a disability. Due to the limited time of the research, this may not be representative for all families.

However, many families got high expenses and finally got into financial difficulties because of the disability of the child. Many families are not able to provide the treatment that the child needs, some families got into a vicious circle that had many negative consequences for the child, the family and the community. This has similarities to the situation of people with disabilities in many countries of the world. The links between disability and poverty are strong; disability may lead to poverty and poverty may lead to disability .

The invisibility of children with disabilities is often an obstacle for achieving social integration. Often children suffer mostly from the social handicap and social integration of children with disabilities is an important goal to uphold.[Parker 1995] In Botswana (1984), rehabilitation efforts aiming at reducing the immediate effect of the impairment the first needs identified among children, and physiotherapy, training in activities of daily living, mental stimulation and schooling was needed [Ingstad 1997: ix, 20, 137, 163].

In Salfeet, all children with disabilities are living with their families. 50 children with a mental disability live at the “Centre for Disabled Children” in the city of Salfeet but they are all from other parts of the West Bank.

The clear impression of the researcher, based on interviews and observations, is that children with disabilities in general are well integrated into the family. Many parents were upset when they realised that their child had a disability, but as the time has gone by, the family has accepted the situation and the family loves the child and treats him/her well, like they treat the other children. The children with disabilities usually take part in family meals, play and visits. Children with mental problems or children showing strange behaviour sometimes do not participate in the meals if there are strangers visiting. One of the boys with a severe mental disability is moving around and

screaming, so the family feels that it is not polite and suitable to let him eat together with their guests.

It seems like what most families find difficult is the lack of understanding and all the questions asked by people in the community. The families also miss information, early detection, treatment and financial support of the health and social system. (see also 13.0)

Many families look upon the situation as the will of Allah and an experience that they are learning from. One mother said she thought the situation of her daughter with a disability was the will of Allah. She was sad in the beginning, but as she accepted Allah's will, she accepted the situation and loved her daughter just as much as she loves the other children. Some other parents told that they are learning from the situation of their child and get new perspectives on life.

The child with a disability might be considered a special case in the family and usually the relatives care very much for him/her. Only two of the informants at this research seemed not integrated into the family; the two children seemed very spoiled by certain family-members and were allowed to do whatever they wanted to. The family-members showed a charitable attitude; they felt sorry for the children. In one family, it might be that one of the family-members were the indirect cause of the disability of the child and had a bad conscience because of this.

In the Palestinian society, the wife usually does the housework; only in rare cases the husband helped the wife at home. This is a problem when the family gets a child with a disability that needs extra attention. The wife gets an additional burden that can be difficult to carry.

It was difficult to assess the attitudes and the experiences of the siblings. The siblings are used to the brother or sister with a disability and they said that they love him/her and they play together. The researcher did not get any information about jealousy, about feeling let aside etc. There were families where the siblings said that because the brother/sister is shouting and screaming, they prefer to take a car if the brother is going with them to the centre. In one family, the siblings did not like the brother and they did not play with him because of his strange behaviour. Some children with disabilities say

that they can do all the things that the siblings can do if they get the possibility, and they can work and help their parents at home.

The sister of a boy with a disability tells that the other children at school did not know about her brother so “she never had any problems because of him”. The family is not hiding him but they are also not telling about him to strangers. Only the relatives, the neighbours and people around who see him when he is out would know about him. Many relatives were sad when they knew about the disability of the child, but as they have got to know the child, they love him and they do not ignore him. The relatives would normally help and support the child and his/her family. The researcher only heard of two families where some relatives were avoiding the child when seeing him/her in the city and saying bad things to others about this child.

There were many stories heard of children with disabilities, especially girls, who had problems to get married. People sometimes think that she is different or that she is not as beautiful as other girls. Girls with a physical disability are often believed to be less able to do the housework or to care for children. Girls with mental disabilities are seen as less intelligent and not as clever wives. Some girls with disabilities were married to a cousin in order to “solve the problem” within the family. The parents thought this was the only choice for the daughter to get married and the best interest of the girl.

### **8.3. Beliefs on disability**

Many people in Salfeet have a western, biomedical approach to disability; saying that problems during the delivery caused the disability of the child. At the same time disability is often explained by supernatural powers. As Muslims, Palestinians have a strong belief in Allah. Palestinian people do not believe that a disability can be caused by “coincidence”.

One mother tells that during the pregnancy she was worried and scared because of the Israeli occupation and this might be the reason for the particular syndrome of her boy as well as it is the will of Allah.

According to the religious leaders people used to believe that the “the evil eye” (the eye that can harm a person in many different ways, like an evil spirit) and in “jinns”(evil spirits) could cause disabilities. The religious leaders hold the opinion that few people believe in this anymore. However, they believe that a jinn may sometimes affect the psychological status of the person but by psychiatric treatment and reading from the Koran he might be treated.

In one family in Salfeet, it was said that the disability of the child was caused by jinns. The grandmother did not believe in modern medicine, only in people who read the Koran in order to get out the jinns. For a year she took the child to a holy place where some religious persons read the Koran and prayed for the jinn to leave the child. The child also got an amulet as a protection from the jinns. The girl used to throw the amulet and the mother also removed it when she changed the clothes of the child. The parents do not believe in jinns and the grandmother thinks this might be the reason why this treatment did not help.



## **9.0. PARTICIPATION IN THE COMMUNITY**

*“A community consists of people living together in some form of social organisation and cohesion. It’s members share in varying degrees political, economic, social and cultural characteristics, as well as interests and aspirations, including health. Communities vary widely in size and socio-economic profile, ranging from clusters of isolated homesteads to more organised villages, towns and city districts.”*

[Helander 1993: 17]

*“All people have an understanding of themselves as belonging to a larger group, defined in geographical, cultural, political, religious or historical terms or mixtures of these. This larger group will constitute a community“.* [Jareg 1994: 6]

In all communities there are human resources, physical resources and structural resources (government, local service, clubs, religious organisations etc.)

The official view held by the WHO and UNICEF is that the reason why children with disabilities are not included is often not the children themselves but the society’s inability to deal with them. The Manager of the General Union of the Palestinian Disabled in Salfeet also holds this view, saying that it is the community that needs rehabilitation, not the persons with disabilities. Social justice implies that services and opportunities should be the same for all people. The various sectors of society should take full responsibility for the needs of disabled people, which is what normalisation is all about (see 7.0.). This points out the responsibility of all regarding the participation and the integration of people with disabilities. [Ingstad 2000]

People in Salfeet face economical and political difficulties; the lack of funding and work in Salfeet gives little income to the families and little tax to the Authorities. The political situation makes it difficult to plan for the future. The newly established Palestinian Authorities has short experience and it takes time before the governmental system will function optimally.

The Mayor of Salfeet states that there is a lack of funding, there is no special program for children with disabilities in the city, not even a program for other children. The

Mayor and the Manager of the Public Health Centre holds the opinion that persons with disabilities should be productive people in the society. The Mayor sees it as the duty of the Municipality to integrate people with disabilities into the society and wants to start this process as soon as possible.

### **9.1. The physical environment**

The physical environment should be accessible to people with disabilities. Adaptation of the physical environment is one of the aims stated in the Standard Rules, rule 5a, and the Law of the Disabled in Palestine, articles 12-17. According to article 15, the local Ministries and the relevant parties have the responsibility for securing the adaptation of the public and private institutions to the needs of people with disabilities.

For the children with disabilities in Salfeet, there are many physical obstacles for participating in the community. It seems like the physical environment is not accessible to many children with moving difficulties. The Municipality and the Ministries have a good plan to improve the standards, but the lack of funding and the political instability makes it difficult to finalise these efforts.

The CBR program is supposed to benefit all people in society. Facilitating improvement of the physical environment would benefit all people in Salfeet and it would also prevent accidents and disabilities in the future.

For persons in need of wheelchairs, crutches or having problems walking, the holes in the roads make it difficult to get around. An additional problem is the lack of zebra crossings and pavements which make it difficult to cross the road in a safe way.

At both public buildings and at private houses there are no banisters by the steps so the children may fall down or they may not be able to climb the steps at all.

Many of the houses and public buildings have “oriental” toilets, consisting of a whole in the floor. For people with certain types of physical disabilities it is very difficult or not possible to sit down like that. At one of the schools there are built a western-type toilet in order to solve the problem for a child with a physical disability.

There are small shops along the main road crossing the city. The shops are usually in the first floor but there are often one or two steps to climb in order to enter, which makes it difficult to enter by a wheelchair. One advantage is that the shops are small and there is only one person working in the shop, so even if you cannot enter the shop, this person may give you whatever you need.

The central mosque is situated close to the bus-station and the other mosques are in the outskirts of the city. There are approximately 10 steps to walk down in order to enter the central mosque, making it inaccessible to people with movement disabilities. (See 11.0.)

The Municipality building is the most important building in the city, it is a four-story building that is not accessible to people with movement disabilities. There are 8 steps to climb in order to enter the 1<sup>st</sup> floor, and there is no lift inside the building. The Municipality building contains a new and very nice library in the 4<sup>th</sup> floor, that many people with disabilities might have benefited from using. At the library there are computers with Internet access for public use, and it is possible to participate at computer courses.

“The Zaytona building”, a large public building close to the Municipality, contains the majority of the local branches of the Ministries. In the 5<sup>th</sup> floor of the building is the Ministry of Youth and Sport and the Ministry of Culture, the department of Jerusalem Open University is in the 4<sup>th</sup> floor, the Ministry of Social Affairs and the Ministry of Labour is in the 3<sup>rd</sup> floor and the women’s club is in the 2<sup>nd</sup> floor. In the first floor there is a cantina and a few small shops. Unfortunately this building is also not accessible to people with movement disabilities. The plan is to place the lift in this building in the near future. The building has a place for the lift, but so far there has not been money for buying and installing it. The present political and financial situation may delay the process of installing the lift.

A child with a disability told that he tried to reach the office of the Ministry of Social Affairs several times in order to be registered. He did not make it and in the end a person from the Ministry came to meet him another place.

Nearby “the Zaytona building” is the Public Health Centre with the local branch of the Ministry of Health. The Public Health Centre is accessible to all people, the Centre is a one-story building and had a separate entrance for people using a wheelchair.

The Ministry of Education has its office 400 metres from the Public Health Centre, that is not accessible to people in a wheelchair. There are several steps to climb in order to enter the first floor and the office of the Manager is in the second floor.

The situation at the schools in Salfet is discussed in no.11.0.

According to the Law of the Rights of the Disabled article 6, all personal transportation means used by persons with disabilities and transportation to and from schools are exempt from fees, customs and taxes. Article 16 states that the Ministry of Transportation is working to adapt the environment to the needs of people with disabilities as well as granting them special discounts in public transportation. (Appendix 12)

The lack of transportation is mentioned by many of the informants as being a major problem for many children with disabilities. One of the reasons why the children cannot participate in many activities is that they cannot reach the places by walking. Within the city-centre there is no public transportation. The only service given is free transportation to school for children living very far away. Most families do not have their own car so if a child cannot walk; the family has to pay for a taxi, which in many situations is too expensive.

One of the boys with a mental disability is much at home; he seldom goes to the city. It is difficult to take him anywhere since he cannot walk and he is heavy to carry. The family use to visit the relatives in the centre of the city every week. The family has no car and they have to pay for a taxi in order to bring their son with them. This gives the family many additional expenses and is an obstacle for letting the son participate in any activities outside of their home.

The bus stop is located in the middle of the city with minibuses going frequently to Nablus and to other places. The taxi station is about 400 metres from the bus stop and for some people with disabilities; this is too far to walk. It is recommended that the bus

stop and the taxi station should be in close physical connection. At least it should be possible to call for a taxi from the bus stop.

## **9.2. Attitudes and public awareness**

The Standard Rules, rule 1, states that one of the preconditions for equal participation of the child with a disability is awareness raising. The awareness raising may be done through public information/education programs via brochures, media, personal communication, teaching at the schools and at the working-places etc. The authorities have the responsibility of performing awareness-raising efforts, but persons with disabilities should be actively involved in this matter. The Law of the Rights of People with Disabilities in Palestine article 3, states that the Ministry of Social Affairs is preparing an awareness program regarding all the rights of persons with disabilities described in the law. It is not clear when this campaign will take place. Article 10.6 of the law states that the Palestinian Authorities aims at working on this issue.

Working on the field of public awareness would presumably contribute much to improving the knowledge of people in the society, which would improve the conditions for all people with disabilities and their families. The General Union of the Palestinian Disabled is a great resource; it works hard on this matter, by general awareness rising in the society and by informing and putting pressure on the Palestinian Authorities.

The attitudes in the community are influenced by many factors like the tradition, the information and the economy of the family and of the community as a whole (see the introduction to part 3 of this thesis). The experience in Salfet and in other locations is that if people know the child with a disability and it's family, they would normally treat them in a good way.

The Mayor of Salfet holds the opinion that Arab people often hide persons with a disability, Arab people do not like to see persons with disabilities in public. People in the community should get information on how to deal with this problem.

According to the Manager of the Public Health Centre there is less stigmatisation of persons with a disabilities nowadays, people are more used to them and know more

about their situation. Some years ago people used to stare at them and look differently upon them but this has changed now.

The General Union of the Palestinian Disabled holds the opinion that the society has a charitable attitude to persons with a disability. People do not believe that a person with a disability can do anything and many people think that people with disabilities should be put in institutions.

A major problem is that persons with disabilities do not get jobs. As an example, it is said that a blind man cannot be a teacher even though he has all the formal qualifications needed. The Manager of the General Union of the Palestinian Disabled in Salfeet is a very clever man and he graduated from the university with good marks in Arabic language. However, there were a need for Arabic teachers but he did not get a job for 10 years. Many persons with disabilities have the skills and the training needed to function but the society is not accepting them. People with disabilities ask themselves what they will benefit from studying for many years when they cannot use their knowledge afterwards. The message of the Manager of the General Union of the Palestinian Disabled in Salfeet is; *“The society needs rehabilitation, not the disabled.”*

Not all children with disabilities are accepted by their families; the General Union of the Palestinian Disabled once visited a family in Salfeet district where the parents even tied their children.

Persons with mental disabilities are worse off than persons with physical disabilities. This was heard and observed when performing this study and stated by persons at all levels of the community.

One of the informants, a child with a physical disability, is ashamed to go to the centre of the city because of the way she looks. If she is going anywhere she usually stays in the car or she covers her face with a scarf. It is the custom of Palestinian women to wear a scarf, but it is normally not necessary for young girls. The neighbours know about the disease and treat her well but other people laugh at her and ask many questions so she stopped going out. She has been to a tourist place with her family during the summer-vacation. She likes to play in the water but she has to cover herself

so nobody will notice her disability. Other girls are not coming to visit her at home, but she plays with her relatives whom treat her very well. She is worried about her future; because of the way she looks and walks, she believes that she will not get married. The girl had to quit school at the fourth grade. Because of her disability and because of her lack of education she thinks that she might also not get a job. If she will not be married, not get a job and be without social security, she will be totally dependent on her poor family and have no possibilities of achieving equal possibilities to participate in the community.

The researcher went out for a walk with this girl at the main street of the city. This was the first time in two months that she was out. She was embarrassed and wanted us to take another road, but after a short time she seemed to enjoy the trip. No people said anything bad to her or looked at her in a bad way. After the trip she said that she would like to try going out again and hopefully she will feel better in the future. The girl has had many bad experiences before, but the researcher holds the opinion that if she would dare to go out more often, then people would get used to her and treat her well.

One of the boys is called “disabled”, people are laughing at him and asking him and his family many questions. It makes him sad, he stops eating and he gets nervous but it does not stop him from going out with his family. He wants to beat the persons treating him badly, but he cannot catch them because of the problems with his legs.

### **9.3. Community participation and mobilisation**

This research focuses on the participation of the child. It is also necessary to see the situation from another angle; to which degree do people in the community participate in improving the conditions of children with disabilities? Community development depends on the participation and the mobilisation of people in the community.

*“Community mobilisation is the process of bringing together all intersectoral social allies to raise people’s awareness of, and demand for, a particular development programme, to assist in the delivery of resources and to strengthen the participation of people to achieve project sustainability and self-reliance.” [Peat 1997: 23]*

By community participation, more can be achieved at a lower cost, giving a more sustainable programme. People involved will learn from the involvement in the programme and be empowered to further development efforts. By participating, the people get a feeling of responsibility and ownership to the programme; people who are actively involved get influence of the program, provide local knowledge and ensure that the program is covering the needs of the people.



## **10.0. PARTICIPATION IN RECREATION AND PLAY**

The Convention on the Rights of the Child, article 31 and the Law of the Rights of the Disabled in Palestine, article 10, no.5 all state the Right of the child to rest, leisure, play and recreational activities. The words rest, leisure, play and recreational activities are all about not working and may seem a bit overlapping. But there are important differences that one should note.

“Rest” means physical and mental relaxation and sleep.

“Leisure” concerns having the time and the freedom to do as one pleases. In order to fulfil the child’s right to rest and leisure, children who work must have enough time for sleep and relaxation.

“Recreation activities” are all activities done for the purpose of pleasure (includes sports, creative and performing arts, crafts and scientific, agricultural or technical pursuits).

“Play” includes activities of children which are not controlled by adults and which do not necessarily conform to any rules. Recreational activities and play are something children do for their own pleasure. Recreational activities include most aspects of a school curriculum whereas play is unstructured and free from adult direction.

It is important to look on how resources for recreational activities are distributed between children and adults. Children with disabilities often need assistance to gain access to or to use recreational facilities.

In many countries today, the main recreational activity for children, especially in urban areas, is watching television. The researcher holds the opinion that in the long run the lack of physical activity may have negative impact on the children’s health and it gives insufficient time for other cultural and sport activities.

According to the “Declaration of the Child’s Right to Play “ there are many alarming trends in society, having negative impact on children’s development. The society is not

aware of the great importance of children's play. There is an over-emphasis on unhealthy competition in children's sports and there is also an over-emphasis on theoretical and academic studies at school. An increasing number of children lack the basic needs for survival and development. The commercial exploitation of children and the deterioration of cultural traditions limit children's possibilities of recreation and play. The number of children working is increasing and their working conditions are often unacceptable. An increasing number of children are also exposed to war, violence, exploitation and destruction. [UNICEF 1998: 420]

### **10.1. Recreation and play in Salfeet**

The Palestinians in general suffer from severe lack of recreational and entertainment facilities, especially for children and for girls/women. Salfeet suffers particularly from this because there are no gardens, no playgrounds, no recreation places, no theatre and no cinema for the people in their leisure time. The financial situation makes it difficult to improve the situation. Salfeet Municipality has a future plan to provide the people with five recreation places in the city; there is a plan to make a stadium with a football playground and a gymnasium for handball, basketball, tennis and volleyball and there is a plan to make an open playground outside the city for sport and a plan to establish a centre for the clubs. At present, there are two clubs in Salfeet, one youth club for boys and a women's club. The women's club started its activities in 1995. The women and girls meet once a month, at daytime. This is a time where most young girls are at school; so only small girls or girls who are not at school can participate. In addition to the meetings, the women's club also arrange some courses. The young men club was established in 1974. It is open every night after 6 o'clock and there are different times for boys at different ages. Some of the boys practice karate and weightlifting or they play billiard and tennis at the club. The club is in the first floor so it is accessible to children with moving difficulties. The other facilities available for young people consist of the municipal playground and the high-school yard. These facilities do not meet the sportive needs of the youth of the city. Karate and football seem to be the most popular sports among boys. The children do sport at school where there are sport-teachers. In the Palestinian culture, the girls are not supposed to do any sport beside of the activities at school.

Salfeet has a very good library in the 4<sup>th</sup> floor of the Municipality building. At the library there are computers with Internet access and computer courses are arranged.

Salfeet used to have a cultural centre with music education but the centre closed down some years ago. The Ministry of Culture has the money for buying equipment for such a centre, but not for the locations. Volunteers used to run the centre and they are now looking for a new place for it.

Some of the children meet after school to play with their friends. However, this is not the custom in all families. In some families the children can play only with the siblings and the relatives in the neighbourhood.

The Ministry of Youth and Sport arrange 2-3 summer camps in Salfeet every year and about 100-150 youth participate in each camp.

In addition to these activities, children in Salfeet also spend much time watching television.

## **10.2. The participation of children with disabilities in recreation and play**

Children with disabilities' participation in recreation and play is very limited. The children play with their relatives and some children at school, but many facilities are not accessible to them. Some children are welcomed to participate in recreation and sport, but because of lack of facilities and/or because of their disability, they cannot participate as much as they want. It may not be very costly or difficult to improve the standards quite a bit. The departments of the Ministry of Youth and Sport and the Ministry of Culture have no special plan for integration of the children with disabilities, but they are co-operating with the General Union of the Palestinian Disabled in order to make such a plan. At the central office of the Ministry in Ramallah, there is a department for persons with disabilities and a special program but so far this is not implemented in Salfeet.

The Ministries state that children with disabilities are welcome to participate in the present activities. As an example, one of the girls with a physical disability use to visit the library and another girl participates in the scout group at school.

10-15 youth with disabilities participated at the summer camps in Salfeet. Only one child with a mental problem participated, but he had to leave after one day. The leaders of the camp found he had special needs and needed special care that they could not provide. The participation of children with disabilities at the camps promotes awareness rising of the situation of their situation. At the last summer camp a boy with a physical disability even gave a public speech. This is a very effective tool in order for other children and parents to get to know these children and their families.

The Palestinian Sport Federation of the Disabled are actively involved in facilitating integration of people with disabilities into the sport activities in the community. The Federation also supports sport clubs and games exclusively for people with disabilities. There are 12 sport clubs for people with disabilities and one integrated sport-club in Palestine. In addition there are five sport-clubs at the rehabilitation centres. [Diakonia & NAD 2000]

One boy falls very often and the mother told the teacher of sport not to let him play. Now the doctors have said that it is good for him to move around so he has started to participate in the sport-activities.

Another boy with problems walking does not participate in any activities but he thinks he can do all the things that his best friend can do if he gets the possibility. He wants to go to the youth club, but he cannot participate because the lack of transportation. In order to solve the transportation problem, he is practising biking every day but it is very difficult because of the deformities of his legs.

One of the girls is playing with her siblings, the relatives and the neighbours after school. Sometimes she even participates in weddings, she goes for visits etc. The main problem is that nobody wants to play with her at school.

A boy with a mental disability is much at home. Children outside the family would never play with him, sometimes they even laugh at him, point at him and they ask many questions. The mother says that the brothers do not play with him but when the researcher visited, the little brother really tried to play ball with him. The boy also likes songs, music and toys with musical sounds.

One child with a physical and a mental disability has no friends outside the house. He wants to play with his relatives, but they do not like to play with him. The relatives are afraid of him because of the fact that he sometimes beats them. Every time he puts his hands on the other children they think he will beat them and they start to beat him back. The siblings want to play with the brother but he does not like to play with them. This child shows very strange behaviour and seems spoiled by his family.

“Samir” also has a mental disability and he is not playing with anyone. Other children do not know how to play with him. However, he feels happy just by seeing other children and being close to them. The mother feels that the relatives treat him well and in the neighbourhood of the family there are many relatives living and the family can leave Samir with them if they need to go somewhere. It has happened that Samir even visits the neighbours alone. Besides, he likes watching TV, listening to the radio and to all kinds of music. Samir enjoys to be around others, if he sees someone he knows, he is following him/her everywhere. Often he is standing at the veranda, looking at other children playing football. He cannot play football himself, but he would like to be close to the yard to watch the others play. He cannot go to the yard without the help of his mother and she is afraid of the reactions of the other children, so she does not bring him there. However, his mother thinks that if the other children knew him they would not laugh at him.

There are no activities for the girls after school, except for a few sport-competitions now and then. One girl with a disability was asked by a teacher at school to participate in a sport-competition but her father refused this. After school the girls have to stay at home. This girl is only allowed to visit her older married sister. The reason for this situation is probably not her disability but because of a culture where girls are very protected.

Facilitating some activities for girls would contribute to a women empowerment program. The activities could be in a bit protected places so the families would not have to worry. There could have been study groups and computer courses for girls at the library, sport activities, hand-craft-courses etc. Many women in Salfet are clever making embroideries, and they could be asked to hold courses in this. The society is constantly changing, and there are many possibilities for making activities for girls. Including girls with disabilities in these activities from the start would improve their social life and their skills and presumably add quality to life.

## **11.0. PARTICIPATION IN RELIGION**

96% of the populations in Palestine are Muslim. The share of Christians is decreasing, due to high emigration rates and lower birth rates than among Moslem. Many Christians are also leaving the area because they find it difficult to live among the Muslims. 90% of the Christians live in Arab Jerusalem and the Bethlehem and Ramallah sub-districts of the West Bank. [Heiberg *et al.* 1993: 43]. The area is considered sacred to both Arabs, Jews and Christians, and Jerusalem is their holy city.

According to the International Covenant on Civil and Political Rights, the freedom of religion means, *“to have or to adopt a religion or belief of his choice, and freedom, either individually or in community with others, and in public or private, to manifest his religion or belief in worship, observance, practice and teaching.”*

The Right of the child to religious freedom and to participate in the religious life is stated in the Declaration on Human Rights article 18, the Convention on the Rights of the Child article 14, in the Standard Rules, rule 12 and in the World Programme of Action concerning Disabled Persons §136. It is not a part of the Law of the Rights of the Disabled in Palestine.

### **11.1. The religious life of children in Salfet**

According to the informants, all people in Salfet are Moslem. There are 4 mosques in Salfet city. At the moment only two of them working, the others are under construction.

Activities at the mosque are awareness raising about religious affairs, teaching the Koran and teaching about social, political and religious matters. Muslims go to the mosque to pray every Friday and the children often come along with their parents. Children from the age of one year are brought to the mosque. According to the Koran, the child should know how to pray at the age of 6 or 7 years.

Because of overcrowdedness at the mosque, the religious leaders have decided that the girls and the women in Salfet are not allowed to enter the central mosque. There are 2

centres in Salfeet where girls at the age of 6-15 may come to learn reciting the Koran. The girls get a small payment as an encouragement for studying at the centre (5 shekel a week/ 10 Norwegian crowns). About 70 girls participate at the religious centres every week.

The Ministry of Islamic affairs arrange religious festivals, trips, summer camps etc. The camps are at daytime, four to five hours for 15-30 days. Girls and boys from 6-15 years of age can participate. The camp offers food and presents to the children. At the camp, the children do sport, draw pictures, and learn about the Koran. In the future, the religious leaders are planning to include a computer-course at the camps.

There is a sharia school in Salfeet district, outside of the city. At the sharia school the children study only school-lessons and religious/Islamic matters.

The Muslim religious leaders control all the religious activities in Salfeet. When talking about religious freedom, it has to be mentioned that Islam is the only religion allowed in this area; people are not free to change their religion. Several informants (also at official level) stated that changing of one's religion was not heard of, but if it would happen this person would be killed.

To sacrifice to Allah is not common in Salfeet, but there are some "holy places" where people can sacrifice animals. One informant told that when a person in the family is ill, the family will pray to Allah. If he gets well, the family may sacrifice a chicken or a sheep. The value of the sacrifice depends on the financial situation of the family.

### **11.2. The participation of children with disabilities in the religious life**

None of the children with disabilities interviewed at this research go to the mosque. Children with disabilities have many reasons why they do not participate in the religious life. Some of them simply do not want to go to the mosque and it might not be the custom in the family to go there. Some girls with a disability say they do not go to the mosque and they do not know how to pray. This is the case for all the girls in the family, not only for them. However, all the children in the family are fasting during the Ramadan except for the father who cannot fast because he is smoking.



Some children with disabilities really want to go to the mosque but face many difficulties that is keeping them away from mosque and the religious life. As mentioned earlier, there are many steps to walk in order to enter the mosque, so if a child has problems walking the steps, he may not be able to enter.

To take off your shoes before entering the mosque is showing respect for Allah and people are not allowed to enter the mosque without taking off the shoes and for some people this is difficult. One of the boys has problems with walking and problems with his balance and he does not manage to walk without shoes or to take off his shoes before praying.

Some children with a skin disease are not welcomed into the mosque. People have told them that they are “not clean enough to enter”.

Children with strange behaviour/mental problems is said to disturb the prayer. One of the boys is kept away from the mosque because he is moving around, screaming and disturbing the prayer and he has never learned how to pray.

One of the boys with movement problems are not able to enter the mosque in Salfeet because of his problems walking. This boy really wants to go there, when he lived in Kuwait with his family, he even went to Saudi Arabia/Mekka for Omrad, a religious festival! (Omrad is like Hajj, you go to Kaba, but not to Mt.Arafat)

The religious leaders seem to have a charitable attitude towards people with disabilities. They encourage people through the orators/religious speech at the mosque to help persons with disabilities, both financially and morally. Many Muslims give zeket; money to the poor (2,5%). Some zeket committees offer financial support for some children at the Centre for disabled children. The Ministry of Islamic Affairs co-operates with the Ministry of Social Affairs. Zeket-committees refer many children with disabilities to doctors or institutions where they can get help.

The view held at the office of the Ministry of Islamic Affairs, is that people with disabilities are treated well: they are not neglected or ignored in Arabic cultures. As an example the Palestinian Authorities have decided to have 5% of their staff consisting of

persons with a disability. The central office of Ministry of Islamic Affairs has a person with a disability working at the office but at the local office in Salfeet there is none.

Normally the boys are circumcised after 1-2 weeks days. The boys with disabilities are circumcised, but some of them are circumcised later than normal. One boy with a disability was circumcised when he was one week; another boy was circumcised when he was 3,5 years old.

It seems like the children with disabilities are not included into the religious activities and the department of the Ministry of Islamic Affairs in Salfeet has no plan for integration. This is a very important issue that should be worked on in the future.

## **12.0. PARTICIPATION IN EDUCATION**

According to UNESCO, education implies “*the entire process of social life by means of which individuals and social groups learn to develop consciously within, and for the benefit of, the national and international communities, the whole of their personal capacities, attitudes, aptitudes and knowledge. This process is not limited to any specific activities.*” [UNICEF 1998: 373]

Also the World Declaration on Education for All (1990) states that education is the foundation for lifelong learning and human development and that all people should benefit from education.

It is not possible to assess all aspects of the life-long learning process. This research is concerned about the possibilities of the children with disabilities to basic education and vocational training, and whether or not they are integrated at the schools.

Declaration on Human Rights, article 26, the Convention on the Rights of the Child, article 28, the Standard Rules, rule 6 and the Law of the Rights of the Disabled in Palestine, article 10 no.3 and article 31, all state the Right of all children to education.

According to the Convention on the Right of the Child article 28, the minimum level is to provide education for children free of charge and that primary education should be available and compulsory for all. Different forms of secondary education and vocational guidance should also be “available and accessible” to all. When it comes to higher education, it should be accessible “on the basis of capacity”.

The World Summit for Children held in 1990 set a goal to make basic education and achievement of primary education accessible to at least 80% of primary school-age children. On a worldwide basis, this seems not to have been achieved. [UNICEF 1998: 372]

The right to education must be achieved “on the basis of equal opportunity”. Lack of resources is often the main obstacle for providing education on the basis of equal opportunities. There might be a lack of budgets from the Authorities, or the families

may be so poor that they cannot send the children to school. Especially children in rural areas, girls and children with disabilities face discrimination against the right to education. Only 2% of all children with disabilities are attending school.

Education is important both as a part of rehabilitation and it can also be seen as both primary and secondary prevention. A high percentage of disability might be a result of lack of information, poverty and low health standards, and can therefore be prevented by means of adequate education. Education of persons who are already having a disability may prevent an additional disability, namely lack of education, job and income as well as lack of the social life connected with this.

All children, regardless of how serious their disability are have the right to education that maximises the ability of the child. The education of children with a disability should be provided “*in a manner conducive to the child’s achieving the fullest possible social integration*” [CRC, appendix 11, article 23.3] Children with disabilities should as a main rule be educated in the mainstream schools with the other children.

Inclusive/integrated education means that persons with disabilities have the right to be educated in the same schools and follow the same curriculum as non-disabled persons.

Special education may be considered if the general school system does not meet the needs of the person with a disability. The purpose of special education is to allow all persons with disabilities, especially persons with communication problem to have access to education programmes adapted to their specific needs. Special education should only be provided for people with severe or multiple disabilities and should be aimed for preparing them for education in the mainstream schools. The quality should be the same as at the general school. The minimum level is that the children with disabilities should be afforded the same portion of educational recourses as children without disabilities.

For some children it may be to their best interest to get education in a separate location. The Standard Rules acknowledge that education of deaf and blind people may be better provided in special classes or schools, in order to meet their special needs.

The UN Special Rapporteur on Disabilities reports that in 10 out of 80 countries that are providing information to the Special Rapportur, the law does not guarantee people with disabilities the right to education.

The Salamanca Statement and Framework for Action on Special Needs Education (1994) also hold the view of integrating children with disabilities into the mainstream schools. According to this Statement this would also provide an “effective education to the majority of the children and improve the efficiency and ultimately the cost-effectiveness of the entire education system” [UNICEF 1998: 307].

Integration into the schools should take place at all levels. The integration process may start at grassroots-level, at the local school. This is seldom seen because of the close link between the school-integration, economy and politics. Often, inclusive education has to be accepted first at national and then at local level.

The integration process at the schools has both a social and a physical aspect. School-life includes both learning, making friends and playing. For children, the social learning process, having friends and being included into the social life is of great importance. The physical environment of the school, the educational plan, the school material etc. must also be adapted to meet the needs of children with disabilities. The teachers should have knowledge and possibilities to give the children with disabilities the same opportunities as other children.

Children with disabilities might need transportation in order to attend school.

The Law of the Rights of the Disabled article 6 states that the child with a disability has the right to free material and the transportation needed for going to school

The CBR programs are all focusing on inclusion of children with disabilities into kindergartens, pre-schools and schools. In the reports commented on at this research (6.4), this has to a various extent been achieved. In all countries there have been various experiences and challenges. At the CBR workshop held by AIFO in Bologna in 1998, one of the problems of the CBR programs mentioned was a lack of access and inclusion of children with moving difficulties in the mainstream primary schools. The evaluation

of the Nicaraguan CBR program showed that integration was much easier in the pre-schools than in the schools.

At the Palestinian CBR program, integration of children with disabilities at the schools has been one of the main achievements. One of the problems reported is that the teachers have got too little training and do not always have capacity and knowledge needed before the integration process has started. This has to be ensured before the integration of the children with disabilities at the schools in Salfeet is to be scaled up.

### **12.1. Kindergartens and schools in Salfeet**

Salfeet has four Kindergartens but no pre-schools. It seems like few children with disabilities attend the kindergartens. Only one of the informants has attended the kindergarten; he was there for 2 months. The teachers were nice to her but the boys at the kindergarten were beating her so she had to leave. Due to the time-limitations, the situation at the kindergartens was not in focus at this study.

Education is compulsory for all children in Salfeet. There are four public schools and one private school in the city. The public schools are for boys and for girls separately but the private school is for both sexes. The public schools have around 500 pupils each, while the private school has only about 30 pupils.

Activities at the schools are scouts, poetry, different performances, “wall magazines” (a kind of newspaper made by the pupils), meetings, sport, school trips, class competitions and reading from the Koran.

The Municipality of Salfeet has done some improvements at the schools and it has future plans for improving the standards. The Municipality has added more classrooms to some of the schools. The increasing number of students makes it necessary to build two additional basic schools for boys and girls and to build two more kindergartens in the future. The Municipality also plan to build a meeting hall for public meetings and student activities and to build laboratories for the two secondary schools. To decrease the burden of the national universities and for developing Salfeet, the Municipality plan to build an Intermediate College.

## **12.2. Education of children with disabilities in Salfeet**

Education of persons with disabilities is a part of the national educational plan. It is said that all children in Salfeet go to school, but the research identified several children with disabilities who were not attending school because of their disability. In addition, the children with disabilities at the schools do not have equal opportunities for participation and they are not all included at all schools.

At the local branch of the Ministry of Education it was said that if the child can manage at least 20% of the schoolwork, he might enter school. There was no explanation on how this would be measured. If the child will not enter school and get the possibilities to participate on equal basis as other children, he/ she will not improve his/her capacity in order to reach this 20% limit.

At the central office of Ministry of Education there is a department for special education but special education is not available in Salfeet. There is a course in Tulkarm, another city at the West Bank, but in Salfeet there is no plan to start up any courses. Only at the secondary school for girls in Salfeet there are a course for teachers concerning the special needs of children with disabilities. The teachers are getting 30 hours of teaching a year by a professor at the university. The reason for this school to hold this course is that the headmistress has prioritised it for 10 years.

Two schools in the district are said to have inclusive education. At the local branch of the Ministry of Education, it was informed that only 2 or 3 children benefit from the programs at these schools.

It may be discussed whether or not the schools in Salfeet are ready for integration of children with disabilities. It seems to the researcher that the process leading to integration has already started at all schools, but the schools are all at different stages in the process. The knowledge of the teachers and the headmaster/headmistress at the school influence the situation of the children with disabilities. At all schools the knowledge about children with disabilities were limited but the situation was better at the secondary school for girls where the teachers had the course.

One suggestion is that the principles and the teachers of all the schools could come together to share experiences of common interest and learn from each other. The staff at the schools would probably benefit from developing a common strategy for information, training of the teachers, co-operation with the family and inclusion of the children. At this early stage the schools would need assistance from outside. In Palestine, inclusive education is functioning in several locations, and teachers from other schools could be invited to share their experiences. Courses in inclusive education could be facilitated and gradually the integration process would develop.

At the same time the CBR worker and the local administration should work with public awareness and facilitate better conditions for the teachers at the schools.

A main problem is that there are a total of 30-35 pupils in each class and the teachers need more time for the children with disabilities. Another problem is that the children have to change teachers too often. In the 1<sup>st</sup> and the 2<sup>nd</sup> grade they have one teacher each year and at the 3<sup>rd</sup> and the 4<sup>th</sup> grade they have 2 teachers each year. From the 5<sup>th</sup> grade on they have one teacher for each subject. It would have been better if one teacher could follow the children for many years.

If children with a more severe disability are to be integrated, one has to give the teachers more time for those children, and the schools need financial support for employing more teachers. If this will not be done, it seems very difficult or impossible to integrate children with special needs into the school. Some children really need a personal assistant or special follow up in order to have equal opportunities to benefit from the education. If this cannot be provided, the children may be present at school but they will not be integrated and benefit that much from it. However, if they would be included in the social life of the school, if they would make friends and play, this would still add quality to their lives.

There has to be a change of the educational system at national level. Teaching children with disabilities must be a part of the teacher's training. The Authorities must try to make more resources available for special education and integration of children with disabilities must be a part of the national and local educational plan.



The problems at school is linked to the lack of health and social services. When the child lack a diagnose and has no training program and service, both the child, the family and the teachers at school feel insecure and have limited possibilities to education and to development of the capacities of the child. One of the children needs a hearing device. When she does not get this, she cannot follow the lessons, she gets bad marks and she loses status among the other pupils.

The co-operation between the school and the family is of great importance. The school needs much information about the needs and the resources of the child and the family and the family need information about the possibilities and the situation at school.

It seems like the co-operation between the school and the family with a physical disability was better than with the families with a mental disability. It is unlikely that the families with a mental disability in reality are more difficult and less co-operative. It might be that having a mental disability is linked to a stronger social stigma and the families are ashamed to tell about the situation. Several families did not really understand the situation themselves which made an explanation to the teacher difficult.. The insecurity of the parents and the teachers seemed to influence especially the children with mental disabilities, leading to frustration, aggression and inability to learn.

Some children with physical problems were not able to participate at the schools. One of the informants had to quit school at the 4<sup>th</sup> grade because of his skin-disease. Some teachers and some few children were nice to him, but most of them ignored him, they told him to go home and clean himself and they told him other things that made him very sad. When the mother explained the situation the teachers treated him better but the other children still refused to sit beside him and they did not want to play with him, he was lonesome at school. Even if it made him sad, he accepted being alone because he did not want the others to see her and to laugh at her. In the breaks he would talk with his brother and sometimes with some few other children.

The situation at the schools reflects the situation in the rest of the community. It is obvious that the children with mental disabilities are worse off than the children with physical disabilities. There is a need of a public awareness campaign at all levels.

A 10 years old child with Down syndrome has never been to school. He was advised not to attend the school, and the parents found that in such a situation, it would be better for the child to stay at home. The parents knew about another boy with Down syndrome who was beaten and treated very badly at the school, and they did not want that to happen to their son.

A 17 years old boy with a mental disability has never been to any kind of school. When he was younger the parents tried to teach him something at home but he did not manage to learn anything. In 1995 the parents tried to take him to the Centre for Disabled Children in Salfeet. The Centre did not accept him because he could not go to the toilet alone. The family also tried to take him to a centre in Amman where they faced the same problem. The mother has never got any help. It seems strange that a child with a mental disability like this is expected to go to the toilet alone. It is not said if this was because of lack of staff at the centre at that time, or if this was the policy of the centres. The family does not want the son to stay in an institution but the parents wish that there were a day care centre where the son could learn something.

Another boy with a mental disability has been told that he may enter the day care centre at the Centre for Disabled Children when he turns 6 years old. The workers at the Centre have said that if he can walk, the teachers at the centre will teach him how to go to the toilet. If this is the case, it seems like the Centre now accepts children who cannot go to the toilet. On the other hand it seems just as strange that they have to walk in order to enter the Centre.

Salfeet has no plan for integration of children with mental problems, learning difficulties or children with Down syndrome into the schools, the Centre for Disabled Children is supposed to take care of them. When the children with mental disabilities are older than 16 years, there is no service at all. The researcher hold the opinion and it is also stated in the Rights and Rules, that children with physical and minor mental disabilities, children with Down syndrome etc. could and should be integrated at the schools. This is difficult in all countries and with the present financial and political situation it seems difficult. The minimum- limit would still be a good day-care service for those children.

### **12.2.1. The primary school for boys**

At this school there are two children with disabilities, one has a physical and the other has both a physical and a mental disability.

The boy with the physical disability seems well integrated into the school. When visiting him, he was sitting at the first row in the classroom and he looked happy. The boy started school when he was 8 years old; one year later than what is normal. The parents and the boy say they have had mainly positive experiences. In the beginning there were some problems, one teacher beat him and treated him badly. This teacher is not at the school anymore, now all teachers are good. The teachers teach him and treat him like the other boys, and they do not ignore him.

The headmaster of the school has been very helpful to this family, and he is trying to adapt the school-environment according to the needs of the boy with the physical disability. The staffs at the school wants to make a pavement in and around the school and to make a new bathroom in order to make the school more accessible.

The classroom of this boy is at the 2<sup>nd</sup> floor, so the headmaster wanted to change it to the 1<sup>st</sup> floor. The boy refused this, he does not want any extra service, he prefers walking up the stairs, holding on to the banister.

The boy is allowed to leave for the break before the other children and he can also leave school a bit earlier than the others so he will not fall when the other children are rushing out.

This boy has many cousins, relatives and many friends at school and in the breaks he plays with them and the other children at school. Sport is difficult because of problems walking so he usually has to watch the games. This boy is very intelligent and this has helped him a lot. Once he joined a quiz, answering many difficult questions. Actually the teacher planned to let him win in any case without telling him, but he won because he was the cleverest!

The school is co-operating with the General Union of the Palestinian Disabled at the Disabled Persons day in December. The school let this boy read the Koran as an introduction for the day.

The situation of the other boy with a mental and a physical disability was not good. First of all this boy has a more severe and complicated disability. In addition, the co-operation and the communication between the parents and the teachers is totally lacking. The school needs information about the disability and the situation of the boy at home and the parents need information about the situation at school. The reason for this conflict is not known, but it makes all parts insecure and frustrated. It seems like an important problem is that both the teachers and the family do not know what kind of disability the child has and they do not know how to teach and to train him.

This boy is at the first grade and he shows very strange behaviour. The teachers say that the boy is not able to learn anything, but the parents think that he can. The teachers have to watch him all the time, they are afraid that he will hurt himself or others. Once he was about to jump from the balcony at school, but the teachers managed to stop him. Some people told that someone is planning to form a committee to dismiss the boy from school.

The researcher met the boy at school and he seemed very unhappy. He was sitting outside the door of the classroom even if the class had started. The headmaster says he goes in and out from the classroom without asking for permission.

### **12.2.2. The secondary school for boys**

The headmaster at this school states that he wants to accept any child with a disability into the school. At the moment, there are two boys with disabilities at the school, one boy has a weak hand and another boy has a learning difficulty. None of these children were informants at this research, so the information about the situation at this school is quite limited.

According to the headmaster, the children with disabilities are treated well, as the others. They have many friends and no one would laugh at them and they may participate in all activities. The boy with the weak hand participates in the scout group.

### **12.2.3. The primary school for girls**

At this school there are four girls with mental disabilities and one girl with a physical disability. There is no special program for them but the teachers try to give them special care, according to their needs and their understanding level. The teachers have no training in special education but they try to make their own programmes. One of the teachers has much experience and knowledge about children with disabilities and she is trying to share her knowledge with the other teachers. She is clever and a good role model for the other teachers and the children at the school.

The pattern is the same at this school as at the primary school for boys. The girl with the physical disability seems well integrated, while the girls with mental disabilities are not integrated. They are present but they are not learning much, they are also not included in play and games and they are not socialising with the other girls.

According to the girl with the physical disability the teachers and the other children are treating her well. They try to help her and they have a positive attitude towards her. Despite her disability, she is cleverer than her siblings.

Some of the girls with mental disabilities have problems concentrating and they are said not to be able to learn anything but discipline in the class. The teachers are trying to teach them how to behave in social settings etc. The girls with mental disabilities do not participate in any activities that require discipline and order. They are present at the morning ceremony but they do not get special duties like reading from the Koran or doing anything like speaking about a subject, sing, do sport exercise or read a poem. These girls are said not to know how to play and they participate only in some selected sport activities.

Some of the girls with disabilities throw books and things in the classroom and one of them damages many things in her classroom. The girls would need a special training program in order to function better. A good example of this is one of the girls with a mental disability who got a training program from Princess Basma Centre, she is now behaving and functioning much better.

The teachers say that one of the girls is especially aggressive and that she beats others. The mother of the girl does not believe this; the girl is never aggressive at home. The girls at school call her names “disabled” and they laugh at her. The mother talked with the teacher and asked her to explain the situation to the other girls, but it did not help. The mother feels that the teachers are ignoring the girl; they let her sit alone in the back of the class. The mother has asked to let her sit with the other children in the front of the classroom but it has not been changed.

The girl has no friends at school, only her sister and her niece. She cannot express herself and the mother is afraid that the teachers are beating her at school. When she was at the 1<sup>st</sup> grade, the mother went to school to observe the situation. She found her daughter very sad and upset, as if someone had just been beating her. The mother took her home without telling anyone or asking for permission. The girl stayed at home for 2 months and no one at school called or asked for her. This girl really wants to learn but she needs more time than the others. The mother wants to take her daughter to a special school in order to learn something.

Since some of the girls with mental disabilities are disturbing the others, some parents of the other girls have asked to put the girls in a special school.

#### **12.2.4. The secondary school for girls**

At the secondary school there are 5 girls with physical disabilities. One girl has a skin disease, three girls have hearing and speech problems and one girl has a problem walking. Last year, there were another girl with a speech problem at this school, she was very clever and is now registered at the university.

According to the headmistress there is always a need to work with integration of all children, but the girls with disabilities at this school are not neglected. The teachers claim that they treat the girls with disabilities like others. This is the only school in Salfeet where the headmistress has prioritised to give the teachers have a 30-hour course in special education each year. It was obvious that this had been important, the teachers at this school had more knowledge about how to teach children with special needs. One of the needs identified by the school is a full time social worker for the school. The one working at the school now is working only part-time, 2-3 days a week.

One girl with a disability is especially clever. In the beginning she faced many problems, but after adaptation of the school situation, everything is well. Since she cannot carry anything, she has books both at the school and at home. She can write but because of problems with her hands she normally does not have to write and to take notes, the teacher is asking her orally in the class. However, at the tests she has to write but she gets more time than the others. Because of her disease she cannot be at school if it is cold. This year, the school will provide a heater for her classroom, so she does not have to stay at home during the winter. She also does not have to stand in the schoolyard during the morning-program; she can wait in the classroom. The girl has many friends at school and the co-operation between the family and the school is very good, which might be the reason for the good situation of the girl.

Another girl with a disability has no follow up at home. The school has faced co-operational problems for a long time, the parents do not come to school and they never call or ask any question. The reason why this girl does not study well is probably due to her hearing and speech problem. The family of the girl is not providing her with the hearing device that she needs. The reason for this might be the financial situation of the family, or it might be a lack of willingness to prioritise the girl in the family. This girl is very shy and she does not have many friends at school. Some girls are nice to her, others are not. When she goes to the toilet, one girl use to open her bag and take her wallet and play with her things. The teacher asked someone to watch the girl who is treating her badly, but it did not help.

Another girls with a hearing problem has got a hearing-device and the co-operation between the school and the family is good. This girl is integrated at school, she has many friends, she participates in play- and sport activities and she gets good marks.

When visiting the school, the girls with disabilities were seen together with friends at school. It was obvious that they liked to be there, it seems like they are well integrated. It must be noted that the girl who does not feel included was not at school that day so it was not possible to observe her situation.

#### **12.2.5. The private school**

At the private school, children with disabilities are in principle not allowed to enter. There are no plan and no interest for inclusive education at this school. Any child who is applying for the school has to make a test before the beginning of the school year. If the child has a disability, he will normally not be accepted into the school.

Contradictory to the school policy, one girl with a hearing disability started studying at the private school this year. She entered because she is especially intelligent; she can hear very little but by the help of a hearing device and by reading the lips she manages fine. When visiting the school, she seemed very happy and integrated into the school.

#### **12.3. Vocational training**

According to The Convention on the Rights of the Child, article 28, the Standard Rules, rule 7, and the Law of the Rights of the Disabled in Palestine, article 10.4: all children have the right to vocational training. This is further stated in the International Labour Organisation (ILO) Convention no.159 [UNICEF 1993; 309] and in the Law of the Rights of the Disabled in Palestine, Article 10.4.

Vocational training is a necessary and important tool in order to integrate persons with disabilities into open employment. According to the Manager of the Public Health Centre, people with disabilities do not need money from the Ministry of Social Affairs; they need to get a job and to be integrated, to be independent, not dependent.

In Palestine, there is a new law stating that 5% of all people working at the governmental institutions should be people with disabilities. Having people with disabilities in the decision-making institutions will presumably have great impact on the situation of all people with disabilities. In Salfet there are not many people with disabilities working at the governmental institutions, only the Public Health Centre has two employees with disabilities. The workers at the Public Health Centre are very well integrated and get the same rights and responsibilities as the other workers.

The department of the Ministry of Labour in Salfet has no special program for vocational training of persons with disabilities. There is a computer course in the fourth floor of the



library that everybody may attend. However, since the library does not have a lift, people with movement disabilities cannot participate.

From 1969 on, there has been a Vocational Training Centre in Salfeet. The girls have learned sewing and the boys have learned welding and construction work.

One of the informants attended the sewing course at the Vocational Training Centre together with her older sister. She has difficulties walking and it was difficult for her to move around at the centre. Because of her disability she did not get much schooling and she could not take notes during the classes, but she was clever sewing. When her sister finished the course, the teachers decided that this girl had to leave too. At this time, the girl was referred to a vocational training centre for persons with disabilities in Nablus. She liked this centre very much but because of the lack of transportation, she had to quit after a short time.

The researcher visited the Vocational Training Centre together with this girl and her mother in order to search for a possibility to get her back into the sewing course. The Manager of the Centre told that unfortunately he just got the message from the central office of the Ministry of Labour in Ramallah that the Centre will be closed down.

After this visit, the researcher, the interpreter and the CBR worker visited the office of Ministry of Labour in Salfeet and discussed this issue. It was agreed that the local staff at the Ministry in Salfeet would discuss the situation with the staff at the central office of Ministry of Labour in Ramallah once again. After the visit of the staff from Salfeet, the Ministry of Labour in Ramallah considered reopening the Centre.

### **13.0. PARTICIPATION IN HEALTH AND SOCIAL SERVICES**

The right to health, some quantitative indicators and a small discussion about health in Palestine is included in no. 5.7. of this thesis. This part will go into more details and give a qualitative description of the situation in Salfeet.

Even if the resources are scarce, all people in Salfeet have the right to health. The people and the Authorities have to work hard in order to develop society to achieve this right.

#### **13.1. Health care in Salfeet**

Salfeet suffers a lot from financial and political situation in Palestine; there is a great need of health facilities. The city has only one Public Health Centre, serving all the inhabitants in the city. Salfeet has no hospital or emergency centre besides a small clinic of the Red Crescent Society. There are only 3 doctors for the whole Salfeet area with about 70000 people.

The Public Health Centre was built in 1974. About 5000 persons are using the services at the Centre every month. The Centre provides medical service, a psychological clinic, mother- and childcare, family planning, immunisation-programs, health education, dentist-service and school-health programs.

The EPI-vaccination program of the WHO is used and well functioning in Salfeet. The program covers more than 98% of the population. The immunisation-coverage of children is 97%, which is very good even compared with western countries like Norway. In Norway, 92-93% of all children under the age of one year are vaccinated [UNICEF 2000: 88].

According to the Manager of the Public Health Centre, who is also the representative of the Ministry of Health, primary health care has to be further developed in Salfeet, as in most other Palestinian locations. The Manager wants to start a good program as a good example to follow for all centres in Palestine.

The resources are scarce and only 20% of the health budget goes to primary health care. The Manager holds the opinion that if the resources would have been effectively used, the share of primary health care should have been 80%.

The Municipality of Salfeet is building a new Public Health Centre. The intention was to provide it with the necessary specialisation, to serve Salfeet and to help solve the crisis of overcrowdedness that the hospitals of the West Bank suffer from. It was planned to be a level 4 primary health centres. The plan was to include a delivery room, an emergency ward, all special clinics and x-ray service at the new centre. Unfortunately, the Ministry of Health has now made it a level 3-health centre, meaning that it will be just the same as the present Public Health Centre.

The Manager of the Public Health Centre and the Mayor of Salfeet agree that they do not need a new building; Salfeet needs new services, especially for women. They work very hard in order to change this back to the original plan. It is important that people from the organisations of persons with disabilities (like the General Union of the Palestinian Disabled) take part in this process in order to prepare for better conditions.

Traditionally, the doctors have been busy prescribing medicine. The Manager of the Public Health Centre holds the opinion that water, sanitation, health, education and gender equity are even more important. Prevention of diseases and community development is needed at all levels. 20000 persons in Salfeet are without proper water supply and there is no system for waste disposal. The waste of the city is sent to the city dump where there is no treatment. This causes environmental pollution that is very harmful to all people. The Municipality is planning to provide a garbage car to collect the waste, to provide containers for garbage and to allocate a new dump and build a wall around it. This would be highly needed; both a lot of waste and pollution is seen all over the city. People are throwing waste all over the city and there is a need for an awareness-raising campaign regarding this matter. The researcher holds the opinion that people have to change their attitude in order to keep the environment clean and safe.

The Israelis have sprayed insecticides and herbicides on the land that lead to water poisoning. The magnitude of this problem is not known, because no laboratories deal with this issue.

The sewage of the houses and some factories of 3 Israeli settlements are crossing the Palestinian land. The pipes are 2 km long and end up close to the water supply of Salfeet. The Public Health Centre has identified bacteria's (streptococcus) in the faeces of people here, probably from this source. In order to solve the problem, chlorine is put in the drinking water so there are no outbreaks yet. Salfeet has only one sanitary inspector in the district and this man alone has not capacity to control the amount of bacteria in the drinking water for the whole area.

A lot of accidents take place in the city, both in the homes and at public places. Many of the accidents could have been prevented. The cars are driving fast and there is a lack of zebra crossings, which leads to car-accidents. (See no. 9.1. of this thesis.)

When visiting the Public Health Centre, a girl that had fallen in a well. She was resuscitated at the Public Health Centre and referred to a hospital in Nablus. If the well had been closed, the accident would not have happened. The girl survived but she might get a disability from being without oxygen for a long time.

Mental health often relates to the economic and political situation of the people, the environment and the resources of the community. The mental health of people in Salfeet has not yet been researched, but according to the present and former political situation, one may assume that many people have many psychological problems. Children's mental health in Palestine is described in no. 5.3.1. of this thesis. There is no reason to believe that the mental health of children in Salfeet is better than in other parts of Palestine. There is an urgent need for an investigation of the situation and a provision of further mental health care in Salfeet. The Public Health Centre has a psychological clinic, but this limited service is probably not sufficient for covering the need of all the people in Salfeet.

The researcher observed many children and youth in Salfeet who participated in the recent confrontations with the Jews. Children were climbing the hills towards the Jewish settlement Ariel and they were throwing stones on the settlers.

### **13.2. Health service for children with disabilities**

There are no special services for children with disabilities in Salfeet. The service is provided with the same quality and within the same system as to other members of society. Another way of seeing it is that the special needs of children with disabilities are not met.

There are many examples of the difficulties of families with disabilities regarding achieving the right to health. The main needs identified by the families of children with disabilities regarding health are:

- There is an need for early detection and diagnosis of children with disabilities
- There is a need of improving the referral system. When this is not working, the disability may develop too far and make treatment and rehabilitation of the child difficult or impossible.
- There is little or no information and guidance about how it is to have a child with a disability and how the particular disability will affect the life of the child and of the family.
- The child with disabilities is in need of a doctor who will get to know the condition of the child and who can follow up the child for a long period of time. The public doctors often have a long waiting-time and the child with disabilities often has to get service from private doctors that are more expensive.

(See the examples below)

NORAD also states the ineffective referral system. A report from 1998 states that there is an overuse of hospital facilities and an underuse of Public Health Care facilities. An investigation in Hebron performed in 1988 indicates that 40% of all patients treated in the emergency rooms at the hospitals could as well have been treated in public health care facilities. [Jareg *et al.* 1998: 17]

The research identified that the families with disabilities have no contact. The parents said that they did not know any other families with the same disability, but many of them wanted to get in touch with others. One mother told that she has seen a child with a similar disability as her son at TV, but she has never met any herself. Another family knew about a child with a similar disability, but they had never met.

The CBR program aims at strengthening relationships and promoting contact between persons with disabilities, their families and their communities. Establishing a network of families with a disability would facilitate an exchange of experiences where the families could learn from each other. Forming an organisation would make the families a stronger pressure group in society and it would lead to public awareness about their situation.

The lack of diagnosis of the children is a major problem. When the children are not diagnosed, they do often not get the right treatment and rehabilitation. One boy was born with his head being bigger than his body. The doctors at the hospital did not notice this and they could not diagnose the boy until he was 7 months old and an ultrasound-test showed hydrocephalus. The family went to another doctor to perform other tests and at that time there were no water in the brain anymore, and the operation was not needed. Now he has a hunchback, speech problems and some other minor problems, but he has not been examined since he was a baby.

Another boy seemed normal at birth but his weight increased only 20 grams the first 3 months of his life. When the boy was 40 days the parents took him to the hospital where the doctors tested him and gave him some medicines and vitamins. The doctors could never examine the child and they could not take CT (computer-tomography) because he was moving around all the time. In 1985 the parents brought him to a specialist who said there was nothing to do for the boy. The mother was advised to feed him and to take care of him, no further help or information was given. Now the boy has a severe mental retardation. The parents feel they have got insufficient help; it has been very difficult to learn everything about the disability on their own.

One girl got fits and probably a mental disability after two overdoses of tablets eaten as a little child. The family knows that she has epilepsy, but they do not know what her other problems are. This gives the family a lot of worries, as the disability is getting worse.

Hamid is 11 years old. He was delivered by breech delivery. The mother did not notice that anything was wrong until the child began to walk and fell very often. Hamid has been to several doctors and has not been diagnosed until a neurologist recently said that

the nerves in his legs are very weak. The family paid much money to treat Hamid but nothing has helped. Because of the late detection of the disability and the lack of diagnosis, the family has not got a training-program and the habilitation of the child has been difficult. The CBR worker advised the family to consult Abu Raja centre in Ramallah to make another test, but the mother has been disappointed so many times that she is not sure if the child will benefit from more consultations.

Wafa is 7 years old. When she was 8 months old, she fell down on the floor and some days later she got a fever. After this occasion the mother noticed that Wafa was cross-eyed and the family went to several doctors who said she did not have any problems. Wafa did not start walking until she was 4 years old and the doctor assumed that she lacked calcium. Another problem was that she could not talk at the age of 4. The parents were worried but the doctor said that she would talk when she got older. This year she started to say some words like her name and some other simple words. Wafa has never got any diagnosis and the parents do not know how what kind of disability she has or what kind of treatment and rehabilitation she needs.

Latifa is 4,5 years old. She was born at home by the help of a midwife. The mother did not notice that she lost the amniotic fluid prematurely, but she noticed that the skin of the child was dry and the girl was blue at birth. Two days after birth, the baby got fits and the parents brought her to a hospital. The fits lasted for one day and one night, her blood sugar was low and she lacked oxygen. Even the parents felt that the situation was serious, the doctors did not tell the parents what was wrong with her. Five months later the “salam-fits” started again (a certain type of fits that looks like a greeting- salam means greeting in Turkish language). Later on, EEG and CT stated that the girl had fits and brain atrophy. After this the family went to many doctors and got several advice and medicine that the child did not benefit from. When Latifa was two years the family brought her to a hospital in Israel where the doctor made a comprehensive examination of her and told the family that she has a specific syndrome. Finally she got the right medicines and the spasms stopped. Now the strong medicines are not needed anymore, she is using another weaker medicine.

Latifa also has problems walking and speaking. She has been to the Red Crescent Physiotherapy centre in Nablus and to a speech therapist that could not do anything for

her. The parents feel it is a great problem that they have not got any information about how it is to have a child with a disability and how to deal with the disability, which makes them worried about the future. The doctors recommended that they should take Latifa to Princess Basma Centre in Jerusalem for rehabilitation, where she can stay for 3 weeks together with his mother and the staff at the centre would examine her and give the family advice on how to train with her. It is not possible for the mother to go to Jerusalem because she has other children that she needs to take care of; there is a need for community-based services.

### **13.3. Maternal health**

Maternal health is understood as pregnancy-related health. The community should be aware of the importance of maternal health and pregnancy care. Community education should include the identification of dangerous signs during pregnancy. Maternal health care is important in order to prevent and to detect disabilities at an early stage.

According to the Mayor, Salfeet has a functioning Mother and Child Health program and all women go to doctors during pregnancy.

The Public Health Centre had a delivery room until 1981 when it was closed by the Israeli military government. The majority of the women in Salfeet now give birth at the hospitals in Nablus, but some give birth at home. The delivery-service seems inadequate and the women have too little information about the risk of giving birth at home.

After delivery there is a lack of follow up, both for the mothers and for the children. There is also a clinic for children under 2 years but not all mothers go there. Some women experienced a lack of care after birth, both from the community's side and from the family's side. One of the mothers interviewed at this research is very thin, pale and tired, but she has to work hard and she has not been to the doctor for an examination. Her child is almost one year old and she is still exclusively breastfeed, she does not want to eat other food. Both the mother and the child are look anaemic. The mother says that she has not got any information of the importance of giving weaning food and other types of ordinary food.



Maternal health also includes preventive maternal health care that includes undesired motherhood. At the Public Health Centre in Salfeet there is a family-planning program that provides counselling and contraceptives. At the West Bank, the contraceptive prevalence rate is 50% (see table 4).

#### **13.4. Rehabilitation services in the local community**

In Salfeet, there are few traditional rehabilitation services for people at home or in the community. Some technical aids, rehabilitation and treatment are available in Nablus. It is obviously too expensive and not a great need of having EEG, CT and MR service in Salfeet, but physiotherapy-service should be provided. Many children in Salfeet would benefit from physiotherapy and speech therapy. There is a physiotherapy room at the Centre for Disabled Children that it is not in use- this room could have been used.

However, physiotherapy and the provision of technical aids should not be the only rehabilitation service. Rehabilitation has to be seen in relation to all other factors mentioned in this research, being obstacles for the equal possibilities to participate in the family and in the community.

The CBR program is focused on adapting the community to the needs of people with disabilities. According to the General Union of the Palestinian Disabled, many persons with disabilities wonder what they will benefit if they go to Ramallah or to Nablus for physiotherapy. When the person returns to Salfeet, there are no facilities and many obstacles for participating in the community. It is important that the provision of physiotherapy service will be linked to the improvement of the physical environment, transportation and the provision of technical devices.

One example of the lack of rehabilitation is a girl who has severe problems walking. She has never received physiotherapy and she does not know how to do any exercises herself. The mother would like the daughter to use a wheelchair if she would benefit from it, but the girl is not so sure if she would like it. Her brother has the same problem as she has and he is ashamed even to use crutches.

Another child also has problems walking, but he is trying to do some exercise himself. In order to get around, he is trying to bike and to walk the steps and use his legs as much as he can. Still, it is obvious that he would benefit a lot from physiotherapy.

### **13.5. Social service in Salfet**

There is a lack of social service for all persons in Salfet, not only for persons with disabilities. The social service is limited and there is no social workers other places than at the schools. People have to pay the medical insurance at the Public Health Centre, 50 shekel a month for the whole family. If the family chooses to have a private insurance, it costs 75 shekel a month. Only under very difficult circumstances, the person with a disability gets a free medical insurance and some money. The Ministry gives financial support only if the father of the child with disability is over 60 years old, if he cannot work or if he is dead. There are also some special medical diagnoses that qualify for financial assistance (ex. Thalassaemia).

Many families have financial problems because of the disability of their child. Many families need to see doctors and visit clinics and hospitals because of the diagnosis, treatment and rehabilitation of their child.

The family of one of the girls has great financial needs because of her disability; they need money for diapers, medicine, visiting doctors, transportation etc. The girl is registered at the Ministry of Social Affairs but the Ministry is not providing any help because her father is alive and her brothers are working.

Another child needs an operation for his eyes but the operation is very expensive, it is difficult for the family to pay for this. Since the Ministry of Social Affairs does not cover any expenses of the family, it is not sure that the boy will have his vision fixed.

Another boy is not registered at the Ministry of Social Affairs or at the General Union of Disabled People and the family gets no financial support. The parents have paid 250 shekel a month for the medicine, but now they have started to buy a new medicine from Israel that costs 100 shekel every month, which helps out their financial problems.

Nahris needs an operation for her legs. She tells that an Israeli doctor can help her, but one visit to the doctor in Israel costs 400 shekel. In addition, the family have to pay 200 shekel a month for the basic medicine that she needs. The Ministry of Social Affairs does not provide medical insurance because her father can work.

One mother wants to take her daughter to an eye doctor in Jerusalem, but an operation might cost 5000 shekel. If the Ministry of Social Affairs will not help her, she will ask for donations in the local community, or she hopes that her brother or some relatives can help the family.

Some parents tell that in the beginning they had many expenses for doctors and for medicine, they had to pay 500 shekel a month for the medicine. The parents applied to the Legislative Council in Salfeet and after a time the family got a paper with President Arafat's signature on the application, so the Ministry of Health/ the Palestinian Authorities has to pay 50% of the expenses. The family might also get help from Palestinian Medical Relief Committee in Tulkarm to pay 300 shekel for a doctor in Israel. Also in another village, the researcher heard about some children that had got President Arafat's signature on an application and got financial support directly from the Palestinian Authorities. According to the official information, this is not according to the formal rules, but exceptions made for a few persons.

The Ministry is supposed to be responsible for rehabilitation and provision of technical aids. This seems not to function in practice, it was not heard of a single case where the Ministry had paid for the technical aids of the child.

The Ministry of Social Affairs supports the Centre of Disabled Children in Salfeet financially, by paying 200000 shekel a year for the water and the electricity of the Centre.

The General Union of the Palestinian Disabled, the Ministry of Social Affairs and the CBR program all have registers of persons with disabilities in Salfeet. It seems like the registers are of mainly the same persons. Only one of the informants were registered at the Union but not at the Ministry of Social Affairs. The difference seems to be that the CBR program has more information about the family situation.

### **13.6. The General Union of the Palestinian Disabled**

The General Union of the Palestinian Disabled was established in Jerusalem in 1990. The first branch was established in Jenin, in 1993. The main centre of the Union is in Ramallah and the Union has 15 branches with a total of 7000 members. Each branch has an administrative committee and a local Manager. Most employees are volunteers; persons with disabilities, only the Manager and the secretary are paid.

The main objective of General Union of the Palestinian Disabled is integration of persons with disabilities into the community. The strategy is awareness rising by lectures, meetings and festivals. At the International day of disabled persons (December 13<sup>th</sup>), the Union has slogans for persons with disabilities, like “Rights to integration and equity”. The Union has some meetings and activities at the schools and it has arranged summer camps and parties for children with disabilities.

The local branch of the General Union in Salfeet was established in 1995. At present it has 260 members but still many persons with disabilities are not members. In 1998 and in 1999, Salfeet was the most active branch of the Union. The Union is actively involved in the decision making process in Salfeet; they are asked when public buildings are built and consulted when new activities are made as well as they are active in the awareness-rising process in the community. This was a very valuable contribution that will benefit the individuals in the long run. [NAD 1999]

The Union has worked many years in order to create an acceptance for the rights of disabled people in Palestine. The endorsement of the Law of the Disabled in Palestine in 1999 was a significant accomplishment that was lobbied for by the Union. The Union has provided guidance and support to the Palestinian Legislative Council and it has mobilised institutions to support the endorsement of the law.

The policy of the Union is not to be a service deliverer, but to do advocacy work and to work on political issues, in order to improve the system that is supposed to provide service to people with disabilities. The Union works on awareness rising through media, seminars and meetings and they hold art competition where different subjects related to disabilities are discussed. Networking with different Ministries and public institutions are another important contribution. Only in particular situations, the

General Union has supported individuals in the field of education, rehabilitation, job opportunities etc. The research identified that all families with a disabilities do not understand the fact that the Union is not a service deliverer. Most families told that the child was registered at the Union, but they did not receive any service and they were disappointed. The role of the Union was clear to most people at official level, but it could be explained clearer to the families with a disabled child.

### **13.7. The Centre for Disabled Children in Salfet**

There are three institutions for children with disabilities at the West Bank, in Hebron, in Jerusalem and in Salfet. The Centre in Salfet serves the whole West Bank and is the only place where children with mental disabilities can live. 50 children at the age of 6 to 16 years with mental disabilities stay here, and 8 children attend the day-care centre. 10 of the children who are living at the Centre have Down syndrome.

The children at the Centre for Disabled Children in Salfet are not integrated into the family and the community, they are often considered “crazy”. When they leave the Centre, they are often not accepted in the community.

Some people say that the Centre wants the family to leave the child but the Manager of the Centre say that they do not want the child to be separated from their families, they want them to be integrated. The Director of the Centre thinks that only the children with severe mental retardation (about 20 children at the Centre) cannot be integrated into the community. There will be a need for a centre for these children also in the future.

The Mayor holds the opinion that the Centre is very good, clean and nice. When visitors come to the Municipality he often takes them to the Centre to show them the facilities. Some other groups from the community also come to visit, most of the groups are from the schools and the clubs. Everybody knows about the children at the Centre, the Director had only read in the newspapers about situations where families have hidden children with disabilities. The children at the Centre do not go to the mosque and they do not know how to pray. This is not always easy for any children with mental disabilities in any country.

Many of the parents of the children at the Centre are relatives. The attitudes of the families towards the children at the Centre vary a lot, some families want to take care of the child and are not ashamed of the child and the situation. This is said to be the case especially in families with a good economical situation. On the other hand, some parents want the children to stay in the institutions even if they are able to live at home. One of the girls at the Centre is 16 years old and she is very clever, she could have lived with her family and taken care of herself but her father want her to stay in the institution. The reason for why he refuses to let her stay at home was not made clear to the researcher. Many families never come to visit the child, while others come to visit often. Some few children even go home to visit their families during summer vacation.

There are about 10 children with Down syndrome at the Centre. Children with Down syndrome are called “mongols” and many people think they are strange. Most of them are not visible in the community, they are not accepted at school and they have few possibilities to learn anything. One example of the opposite is one boy with Down syndrome among the informants at this research. He stays at home and people in the local community know him and they like him.

It is difficult for a child with a mental disability to get a job when they leave the Centre. People in the community are not used to them, and they do not think that they can do anything. One of the boys who have lived at the Centre has a minor mental retardation but he managed to get a job in Ramallah, but the colleagues at the working- place protested and he had to leave the job.

The Director of the Centre holds the opinion that the local communities are not prepared for the integration process. There is no awareness of the situation of children with mental problems, many people do not know how to deal with them and they are afraid of them. There is a need of a public awareness-campaign where for example the television and the magazines could contribute. The researcher agrees with the Director of the Centre that public awareness is needed. Even in countries like Norway, the integration of people with certain mental disabilities has failed because of lack of public awareness and efforts to promote social integration. The focus has been on the medical part and the communities have not been prepared for receiving and integrating these persons. The researcher also holds the opinion that some of the children with mental

disabilities may be difficult to integrate. If the child is totally dependent on assistance, it may be too difficult for the family to care for him/her at home. Even if the child has to stay most of the time in the institution, much could be done in the field of co-operating with the family. The family should get more responsibility and spend more time with the child at the institution, and the child should be able to visit its home more often etc.

### **13.8. Specialised services**

Abu Raya Rehabilitation Centre in Ramallah has 27 beds for people in need of rehabilitation services. The Centre has a separate Spina Bifida unit as well as it has an outpatient service, serving about 40-90 people every month. The staff has training programs at the local schools, and the Centre works on developing sport-activities for people with disabilities. There is a good library at the Centre, where people interested may borrow books about health and rehabilitation. In addition to all this it is also possible to rent or to buy technical aids from the Centre.

Jerusalem Princess Basma Centre for Disabled Children is developing as a national referral- and resource centre. The Centre has a special education department; it has a recreational therapy department, an in-patient physiotherapy department and an outpatient physiotherapy department, a nursing department, an occupational therapy department, a speech therapy department and a social work department. The Centre also has a mother's empowerment program. This Centre is developing a rehabilitation medical library. In addition to this there is an orthopaedic workshop and an ophthalmic screening program.

Betlehem Arab Society for Rehabilitation is another national rehabilitation provider. The Society has both inpatient- and outpatient clinic. The Society provides audiology service, physiotherapy, speech therapy, occupational therapy and technical aids. It works with vocational training and it promotes educational service, social- and sport activities for people with disabilities.

From what was heard from the CBR team, it seems like the Abu Raya Centre in Ramallah and the Princess Basma Centre in Jerusalem are very good centres for training of child and teaching the family. The mother and the child can stay at the

centres for one or two weeks in order to learn how to deal with the child and the family situation, free of charge. However it is often difficult for a mother from Salfet to leave her home and the other children to go to Ramallah or to Jerusalem. There is a clear need for community-based services that the CBR program aims to facilitate.



#### **14.0. GENDER**

When researching the situation of children with disabilities, it is important to identify whether there are differences between the situation of men and women, girls and boys. Gender equity must be seen in relation to the culture in which people are living, but it should be a goal for all cultures to achieve. Gender equity does not mean that man and woman are equal; it means that they should be treated equally, have respect and equal opportunities to use their resources in society. Gender equity and Human Rights for women and girls with disabilities are stated in the Standard Rules, no.15 of the introduction of the Rules, The Convention on the Economic, Social and Cultural Rights, article 3, The Universal Declaration on Human Rights, article 2, Manifesto by Disabled Women in Europe (European Union, Bruxelles 1999) and in the Beijing Declaration and the Platform for Action (The UN conference on Women 1995).

The CBR program gives extra attention to the situation of the girls with disabilities and the girls are supposed to be the main beneficiaries of the CBR program. There is a lack of documentation of the gender aspect of the CBR programs.

The role of a girl/woman with a disability is reflecting the role of women in society in general. Human Rights, Gender and Democracy are closely linked. It is said that girls/women with disabilities face a double discrimination, both in terms of gender and also because of their particular disability. The main obstacles for equalisation of opportunities between men and women in Palestine is said to be old traditions and culture, lack of supporting groups and lack of help and understanding from the Palestinian National Authorities [Nobel *et al.* 1997: 24]. The Manager of the Public Health Centre stated: “If you do not provide gender equity you will never achieve health.”

Both the fertility rate and the life expectancy in Palestine are high. Death rates are higher for girls. The reason for this is not clear, but Bergström holds the opinion that the reason is that the girls get less attention. [Bergström 2000: 37]

Women in Palestine are not allowed to have children out of wedlock. When this happens, the mother usually get the blame and one seems to “forget” that the man involved also has a responsibility. The World Bank mentions killing of young women by family

members due to “disgrace of family honour” as a serious Human Rights and reproductive right issue in Palestine [Jareg *et al.* 1998: 25]

The common opinion is that in general Palestinians prefer to have boys, but if a girl is born, the parents love her as much as they would have loves a boy. Many informants stated this and it was also the impression of the researcher. From the observations made, it seemed like the boys and girls were loved and cared for the same way, but it seemed like the boys have higher status in the family and some of them were quite spoiled. This may reflect the fact that a man has higher status than a woman in the Palestinian society. Boys are supposed to contribute more to the family economically and will often get more support from the family. The girls get married early and they are not supporting their family financially. Girls are more protected; there are more things that they are not allowed to do. As an example, the girls are not supposed to go out after school and they have to cover their hear and they are not supposed to participate in sport-activities.

The Director of the Centre for Disabled Children is a woman. The Centre was established in 1983 and in the beginning, only boys were admitted to the Centre. People thinks that the girls should stay at home where it is easier to control and protect them. Still there are more boys than girls at the centre (34 boys and 16 girls). However, the Director says that the Centre accepts girls as much as boys and there is no difference in the treatment of the children.

According to the Manager of General Union of the Palestinian Disabled in Salfeet, the girls do not have any rights in the Palestinian society, and girls with disabilities are even worse off. Sometimes the girls do not even get education; the parents think that the girls will not benefit much from it. When the girls with disabilities are getting older and want special things like beautiful clothes, shoes, perfume etc., they might not get it.

The CBR program have identified that in particular deaf girl are overprotected and is kept away from social gatherings and education.

In one family visited at this research, the daughter and the son have the same physical disability. Both of them needed an expensive operation, but only the son got it. The son is also spending his time with friends in the city every day, while the daughter has to be

in the house all the time. When we met her she had not been outside the house for several weeks.

Girls with disabilities face great obstacles in order to get married and to get children. Several of the girls and the parents of girls with disabilities interviewed told that they believed the girl would have problems getting married, or they believed that the girl would not get married at all. In Palestine, the couples often get married without having known each other for a long time. When the man do not know the girl very well, the physical appearance of the girl gets even more important. If the girl has a disability or if she is not as beautiful as others she might not be chosen for marriage. Another problem faced is that if a woman gets a disability after she has been married, there is a greater risk that the husband will leave her or that she may be judged not competent to care for her children.

According to the CBR program, a woman who gives birth to a child with a disability is losing respect in the family and in the community. The husband, the rest of the family and the community often blame her and the husband may threaten to leave her or to get married to a second wife. This was seen in one of the families, where the first wife got two children with disabilities. After some time, the husband got married to another wife.

Both in developing and industrialised countries, women are often the main caregivers. In Palestine, the women have little formal support from the community. This gives an additional burden to the women; the responsibility of caring for the child, a husband or a parent with a disability is put on her shoulders and it limits the freedom and the possibility to take part in other activities. The men with disabilities have a special male problem; they may lose respect if they are not able to be the breadwinner of the family.

An important aspect is; who are the decision-makers in the community? In Salfeet it is almost only men, both in the family and in the community. At the Municipality, there are only one woman employed and in all the Ministries, there are no women employed. It may be difficult for the men to fully understand and work to improve the condition of women in society. This might be a reason why the girls and the women benefit less from the services given.

## **15.0. DISCUSSION WITH RECOMMENDATIONS**

The hypothesis of this research is that the possibilities of children with disabilities to participate in the family are quite good and the possibilities to participate in the local community are very limited. The research has identified ongoing processes, needs and resources in the family and in the community, and it has found the hypothesis to be true. The impression of the researcher is that the CBR worker knew most of the needs and resources in Salfeet already, but the situation had not been documented as detailed as it has been at this qualitative research. It has also proved important to see the situation in comparison with the rights and rules valid for children and use this as a long-term goal to achieve. Even if the rights might be influenced by western thinking and culture and seem quite idealistic to achieve in many countries, they are important ideals to uphold.

Some evaluations of CBR programs have been found, but the literature review identified that there is a great need of more evaluations in order to identify the result and the impact of the CBR programmes. When starting up the CBR program in Salfeet, the aim and objectives of the program must be clear and all steps of action taken have to be documented in order to be able to evaluate the programme at a later stage. This research might be used as a background for an evaluation.

Given the present political and economical situation, it seems difficult to improve the services for children with disabilities in Salfeet. As the “new Intifada” is still ongoing, there will be more people with disabilities every day, at the same time as there will be less resources to cover their needs. In general, most sectors in Salfeet lack a plan for developing the services for people with disabilities. The normalisation process, that the various sectors of society should take full responsibility for the needs of people with disabilities, is still at an early stage. However, the researcher got the clear impression that many people in Salfeet are interested in, and willing to work for Human Rights, in order to provide equal opportunities for all people in society, but there is a need for support in the integration process.

The greatest resource in Salfeet is the family, but the local community also has many resource persons. The Mayor of Salfeet, the Manager and the staff at the Public Health

Centre and at the Manager Centre for Children with Disabilities and some teachers and headmasters are among the resource persons in the local community, with experiences and knowledge to share. Great improvements of the situation of children with disabilities may be done by using the existing human and material resources effectively, by prevention measures and by awareness rising. People in Salfeet should not give up to work for Human Rights and equity for all, both in the private and in the public sector. To implement changes in the family or in the community takes time, it takes commitment and it takes hard work. The aim of the integration process is that people with disabilities should be full members of society, on equal terms, but with ample consideration taken to their special needs, which includes overcoming stigma and providing equal opportunities.

Lack of community involvement in the situation of people with disabilities is a problem faced in many countries around the world, and this is also the main obstacle for the participation of children with disabilities in Salfeet. Even if the community has resource persons, the majority of the people seem not to be actively involved in promoting the participation of children with disabilities. The research identified that having a child with a disability is often seen as a “problem” of the family, and the other community members do not necessarily feel a responsibility. However, promoting the participation of children with disabilities is a human right issue that all people have a responsibility of contributing to. The social integration of all would improve the quality of life for each person contributing to this process. The families with a disability have great knowledge and experiences that many of them would have shared if they had got the opportunity. Knowledge is a key factor in order to promote the participation of the child. People who know a child with a disability and its family do in general have a positive attitude towards them. Community awareness- and knowledge would change the attitudes, lead to improved co-operation between the families and the rest of the community- and enhance the social integration.

Establishing contact and communication with people in the same situation is ways of empowering people by letting them share their experiences, their resources and their needs with someone who can understand and support them. The families with disabilities would come up with new ideas that would benefit all, and together they would be a stronger pressure group in society. At present there is little contact between

the families with disabilities in Salfeet, and the CBR program is recommended to support the establishment of formal and informal communication. Parents groups, youth groups, children's groups etc. could be established, either as informal settings or as separate organisations, eventually linked up to the General Union of the Palestinian Disabled.

The CBR program in Salfeet is implemented in co-operation with the Ministry of Social Affairs, which is also recommended by literature. However, there seems to be a need to improve the co-operation between the CBR program, the Ministry of Social Affairs and the General Union of the Palestinian Disabled. The relationship is good, but some of the work seems overlapping. One example is that all three parts have more or less the same list of people with disabilities, but the CBR worker has more information about each of the persons. The researcher holds the opinion that it would be useful if all information about the children with disabilities would be gathered at the Ministry of Social Affairs, that has the final responsibility for supporting people with disabilities. Doing this, one has to assure the confidentiality of each person. It seems like the Ministry of Social Affairs could be more actively involved in the implementation of the program. There is a danger that the Ministry leaves the responsibility of the children with disabilities to the CBR worker. The Ministry needs to employ social workers and other staff to facilitate equal opportunities for people with disabilities. It would be a cost effective and very useful tool to employ a public physiotherapist who could work at the physiotherapy room at the Centre for Children with Disabilities.

The General Union of the Palestinian Disabled in Salfeet do a very good and important job, but there is a need to clarify it's role to the parents of the children with disabilities.

The need for improvement of the health and social services in Salfeet is clear. The most cost-effective health interventions are preventive health care, which should be emphasised, at all levels. Studies have shown that for every dollar invested in children's health during the first three years, one gets about 8 dollars back as saved future cost of health and social services [UNICEF 2000: 2]. First of all, the mother and child health program has to be strengthened. The mothers should get closer follow-up during pregnancy and delivery, it is important to detect and to treat disabilities at an early stage, as a secondary prevention measure. In order to do this, it is recommended to train

and to employ more public health nurses and midwives. The provision of a delivery clinic at the new “hospital” would also prevent- and identify disabilities at an early stage. As it is now, there should be better contact between the hospitals in Nablus and the Public Health Centre in Salfet. As soon as a child with a disability is born, this should be reported to the Public Health Centre and actions for follow-up should be taken. The Public Health Centre has a good primary health care program that the CBR program could link closer up to. The referral guidelines are however not clear, it seems a bit coincidentally where the doctors are referring the patients. The suggestion of the researcher is to make a referral-map to be distributed to all doctors in Palestine, which would be a cheap and effective tool.

Given the political situation, there is a need to be aware of the mental health status of children in Salfet, and to improve the mental health care in the community. A research of the mental health of children in Gaza identified severe psychological traumas from growing up in a situation of war, and it is expected that the situation in Salfet is quite similar [El Sarraj 1993]. The mental health status of people in Salfet is expected to have worsened lately, due to the confrontations with the Jews. Children are once again throwing stones and taking part in the clashes. The researcher holds the opinion that the parents and the Palestinian Authorities have to stop the children from taking part in hostilities, in order to prevent mental and physical disabilities, to save lives, and to fulfil the Convention on the Right of the Child article 38.3; “States Parties shall take all feasible measures to ensure that persons who have not attained the age of 15 years do not take a direct part in hostilities” (Appendix 11). President Arafat himself has officially announced that this Convention should be followed in Palestine.

The Ministry of Education has to take further responsibility for the integration of children with disabilities into the kindergartens, schools and vocational training centres. Including children with disabilities into the educational system would empower people with disabilities and make them visible in the community. The first step that has to be taken to prepare for the integration- process is providing training for the teachers. Some of the teachers at the schools already show great interest in providing inclusive education and some of them have experience in teaching children with special needs. The secondary school for girls may be seen as a good example to follow, providing courses in special education and facilitating the integration of children with disabilities

into the schools. A suggestion of the researcher is that a teacher from the course in special education in Tulkarm could come to Salfeet to train the teachers at all schools in the city.

Too many children in each class and the frequent changing of teachers make the integration process difficult. It is recommended that each class should follow one teacher for several years, a system that would benefit all teachers and pupils at the school. If a child with a disability is to be included and get equal opportunities for learning, there might also be a need for a personal assistant for this child.

It may be discussed whether or not it is possible and desirable to integrate all children into school. At least at this stage, children with severe mental disabilities cannot be integrated into the mainstream educational system, but they should be given the possibility to develop their capacity in some way or another. The Palestinian Authorities should ensure that no children should be separated from his/her parents against his/her will unless it is necessary for the best interest of the child. The day-care services at the Centre for Children with Disabilities in Salfeet could be expanded and/or there could be new services developed. Other children with less severe mental disabilities should be integrated into school. Especially children with Down syndrome have great resources and potential for learning if they get the possibility and some extra support.

There are limited possibilities for organised recreation-and play activities for all children in Salfeet and children with disabilities are even worse off, they have very limited possibilities to participate. However, several of them are participating in recreation and play at home, with the siblings or other relatives and friends. Still, there is a need to develop a plan for improving the recreation-and play activities, including sport and cultural activities, for example art, music, dance or theatre.

The physical environment in Salfeet has to be further adapted to the needs of people with disabilities. In particular there is a need for a lift in “the Zaytona building” and in the Municipality building. There is also an urgent need for transportation of people with movement difficulties. In addition to this, Salfeet also has severe environmental problems that lead to disabilities and illnesses. The polluting sewage-pipes from the



Jewish settlement Ariel has to be moved away from the water supply of Salfet. There is a need for the Palestinian Authorities to put harder pressure on the settlement in order to solve this very important issue. Given the present political situation, it seems impossible to establish a communication with the Israeli Authorities, but as soon as the situation stabilises, this issue has to be worked on. There should also be an awareness-rising campaign in order to change the attitudes and the actions of the Palestinian people, stressing the importance of keeping the environment clean and not throw the litter in the environment.

Providing gender equity would facilitate the participation process and promote health. A suggestion is to use the women club for different programs empowering women (courses, meetings etc.) and for an awareness rising campaign. Palestinian women often get married very early, and have little possibilities for studying and qualifying for jobs that will make their voices heard in the decision-making process in the community. Marriages between relatives and early marriages may cause disabilities. According to the Manager of the Public Health Centre, there is a need for a new Law regarding marriage, in order to promote the public health. The researcher holds the opinion that the religious leaders should take stronger responsibility in the awareness rising process.

Many families face economic problems and income generation projects would benefit the whole community. Save the Children in Nablus has already started up this activities and the CBR program is recommended to co-operate with them.

World-wide, it is said that children with disabilities have been hidden and neglected, but these statements have also been questioned by some researchers. Also in Palestine, it is said that children have been hidden and neglected, but this research did not identify any families in Salfet where this was the case. However, in some situations the family-members or the child itself were embarrassed, ashamed or afraid to participate in the community-life. It is also said that in Palestine, people with disabilities have higher status and are less stigmatised because of the many war-victims who has got higher status after the Intifada. This was not identified at this research, it might be the case for some older boys/men, but it seems not to be the case for the children identified at the fieldstudy. The aspect of stigma is also linked to the way people are labelled and categorised. Worldwide, the term "Person with a disability" is commonly used, because

of the increasing social approach to disability, the term is seen to be less labelling and stigmatising. In the Arabic language, the word “disabled” is linked to a strong stigma and there is a need for a discussion around the use of this word. In Nablus and in Salfeet, all people the researcher talked to used the word “disabled” and in the reports from the CBR program the term “disabled person” is used. The Manager of the Public Health Centre holds the opinion that the term “differently-abled persons” is more suitable. Another suggestion is “persons with special needs”.

The personal impression of the researcher is that the CBR program is very good and sustainable. The CBR programmes have great importance in many parts of Palestine and will presumably also have a great influence in Salfeet. The NGOs are still a very important factor in developing Palestine. A major criticism of many NGOs is that they work independently and autonomously and that their programs are limited to local settings. Only in a few locations, the NGO-programs are turned into a sustainable national program, like it has in Palestine.

The CBR program is a part of the civil society, representing the “private not for profit” providers. *“The influence of civil society on health and health care depends on the recognition of its role as a partner in primary health care, on its success in the scaling up of activities, on its co-operation with the State and business sector, and on networking”* [Jareg 1998: 819]. In order for the CBR program in Salfeet to secure long lasting improvements it has to “scale up” its activities. Some suggestions for “scaling up” the program follow;

1. Additive strategies – aiming to increase the size of the programme and the organisation.
2. Multiplicative strategies - focusing on networking, policy influence, legal reforms and training.
3. Diffusive strategies – by spreading the program informally and spontaneously.

[Jareg 1998: 820-821]

The CBR program in Salfeet will probably use a mixture of strategies to expand the program. The program will increase in size by involving more and more people and public institutions, focus on networking with the Ministries and the Municipality of Salfeet, as well as spread the program informally, ad hoc. The CBR program is planned

to go on for a long time; the CBR worker is not planning to withdraw from the project in the near future, but her visits will be less frequent after some time. The researcher recommends focusing on multiplicative strategies, turning the CBR program into a local program run by the Authorities in Salfet. This implicates that as the program is increasing in size, the CBR worker should aim at withdrawing from the district after some years and leave the responsibility to the Authorities. The CBR team in Nablus could be used as a resource centre, where the local administration of the program could get advice and training whenever needed.

The success of the CBR program depends on the co-operation of all persons involved, included the governmental institutions, the NGOs and the organisations of persons with disabilities. An exchange of information and ideas will give a stronger and more sustainable service in the time to come. People having the power and the authority in Salfet should be actively involved in the program, but people with disabilities and their families should be the main beneficiaries and the owners of the program. The services should promote equity and health for all. Health, social justice and Human Rights are closely linked together. All people have the right to a life in dignity. The society should show solidarity, not charity and there should be integration, not segregation.

This research is intending to be a small contribution to an awareness-rising process and a discussion that presumably will continue in the time to come. This research has been very interesting, and the researcher has learned a lot from the people in Salfet, the CBR program and other people met at the West Bank. To get to know a new culture takes time, and it would have been preferred to stay longer in the area to learn more. The hospitality and the friendliness of the Palestinian people made a great impression on the researcher, who hopes to return to Nablus and to Salfet, to see the development of the CBR-program and to meet all friends and co-workers again.

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## **APPENDIX 2: SEMI-STRUCTURED INTERVIEW-GUIDE**

### **PARTICIPATION OF CHILDREN WITH DISABILITIES IN THE LOCAL COMMUNITY AND IN THE FAMILY.**

**1. What are the normal arenas for participation for children regarding:**

- Religion
- Cultural activities
- Recreation
- Play
- Sport etc.

**2. Is the physical environment accessible to children with disabilities?**

- Public buildings
- Local transportation
- Recreational-sport and play arenas etc

**3. Are children with disabilities participating in the family-life?**

- Do they live with their families?
- Do they take part in family-meals, decisions, talks, play, visits etc.?

**4. Are children with disabilities participating at the kindergartens, pre-schools and school?**

- Is education of persons with disabilities an integrated part of the national and local educational system?
- Are the parents of children with disabilities and organisations of persons with disabilities involved in the education process?
- Is special education available?
- Are teachers trained to understand and to meet the needs of children with disabilities?

**5. Do children with disabilities get medical care and social service?**

- Is the service provided with the same quality and within the same system as to other members of society?
- Are disabilities detected at an early stage?
- Are medical personnel and social workers trained and equipped to care for children with disabilities?
- Have medical personnel access to relevant treatment methods and technology?
- Which rehabilitation services exist?
- Which support services exist?

**5. Do children with disabilities have possibilities to participate in cultural activities?**

- Theatre
- Cinema
- Different children organisations and activities etc.

**6. Do children with disabilities have possibilities to participate in recreation- play and sport- activities?**

**7. Do children with disabilities have opportunities to participate in the religious life of the community?**

- Mosque
- Church

**2. Are there differences between boys and girls regarding the participation of children with disabilities in the family and in the local community?**

### **APPENDIX 3: CHECKLIST FOR THE SEMI-STRUCTURED INTERVIEWS**

The guidelines are formulated mainly by the use of the norms set in the Standard Rules corresponding to the objectives of the study [UNICEF 1998; 662-664].

1. **Normal arenas for participation.** What are the normal arenas for participation for children regarding religion, cultural activities, recreation, play and sport activities in the local community?

To identify this, children and the family of children without disabilities, teachers at the schools, people at sport, cultural and religious organisations and personnel at health-institutions was interviewed and observations was made. The findings will influence questions number 2-9.

2. **Physical environment.** Do children with disabilities and their families feel that the physical environment in the local community is accessible? To what extent is the physical environment actually accessible to the children with disabilities?

Children with disabilities, their families and persons in organisations for persons with disabilities were interviewed. The researcher, the interpreter, the CBR worker and a child with disability observed and described the physical environment. Arenas observed are public meeting-places, shops, schools, playgrounds, mosque, church, health clinics and hospitals etc.

3. **Family.** Do the children with disabilities live with their families? Are they included in the family-life? Do they take part in family-meals, decisions, talks, play, visits etc.?

Children with disabilities and their families, organisations for persons with disabilities and persons in the community administration were interviewed. The Centre for Children with a Disability was contacted and interviews were performed.

4. **Education.** Are children with disabilities integrated into kindergartens, pre-schools and ordinary schools? Is education of persons with disabilities an integrated part of the national and local educational system? Do schools provide interpreters and support services? Are parent groups and organisations of persons with disabilities involved in the education process? Is special education available? Are teachers trained to understand and to meet the needs of children with disabilities?

Children with disabilities and their families, teachers at the schools and workers at the General Union of Disabled Persons, people from the community administration and from Ministry of Education were interviewed.

5. **Health and social.** Do children with disabilities receive social services and medical care? Is the service provided with the same quality, within the same system as for the other members of society? Are disabilities detected at an early stage? Are medical personnel and social workers trained and equipped to care for to children with disabilities? Have medical personnel access to relevant treatment methods and technology? Which rehabilitation-services and support-services exist?

Children with disabilities and their families, the Manager of the public-health clinics/the representative of Ministry of Health was asked. General Union of Disabled Persons, persons at the community administration, and Ministry of Social affairs was interviewed.

6. **Culture.** Do children with disabilities and their families feel that there are equal possibilities to participate in cultural activities? Are the places for cultural performance and services accessible to the children with disabilities?

Children with disabilities and their families and persons working at cultural organisations and the Ministry of Culture were asked. The researcher observed the places for cultural performances and services.

7. **Recreation, sport and play.** Do the children with disabilities and their families feel there are equal opportunities for participating in recreation, play and sport activities? Are the arenas for play, sport and recreation accessible to the children with disabilities? Are the Sport-organisations actively involved in making the sport –activities accessible for the children with disabilities? Do organisations of persons with disabilities feel that organisers of sport and recreation are consulting them if developing the services for persons with disabilities?

Children with disabilities and their families were interviewed. Persons at organisations for persons with disabilities, people at the schools, the sport organisations and the Ministry of Youth and Sport were interviewed.

8. **Religion.** Do the children with disabilities and their families feel they have equal opportunity to participate in the religious life of their community? Are the arenas where the religious activities take place accessible to the children with disabilities? Is the religious literature accessible to children with sensory impairments? Are the organisations of persons with disabilities consulted if religious organisations are developing measures for equal participation in religious activities? Are children with disabilities participating in initiation-ceremonies?

Children with disabilities and their families, leaders at the mosque and at the Ministry of Islamic Affairs were interviewed. Observations took place.

9. **Gender aspects.** Are there differences between boys and girls with disabilities regarding participation in the family and in the local community?

This is a cross cutting issue in all other questions. On the basis of all interviews, the research will try to draw some conclusion regarding this issue. (See appendix 2)

**APPENDIX 4: LIST OF ABBREVIATIONS AND ACRONYMS.**

AIFO	Associazione Italiana “Amici di Raoul Follereau”
CBR	Community Based Rehabilitation
CRC	Convention on the Rights of the Child
DIS	Diakonhjemmets internasjonale senter/international center. (Centre for Partnership in Development)
FAFO	Fagforening Forskningsstiftelse
GUPD	The General Union of the Palestinian Disabled
HDIP	Health Development Information Project
Israeli MFA	Israeli Ministry of Foreign Affairs
NAD	Norwegian Association of the Disabled
NGO	Non Governmental Voluntary Organisation
NORAD	Norwegian Agency For Development Co-operation
PCBS	Palestinian Central Bureau of Statistics
PLO	Palestinian Liberation Organisation
PNA	Palestinian National Authority
PNC	Palestinian National Council
SIDA	Swedish International Development Co-operation Agency
SHIA	Swedish Organisation of Disabled Persons
UD	Utenriksdepartementet, (The Norwegian Ministry of Foreign Affairs)
UN	United Nations
UNRWA	United Nations Relief Work Association
UNICEF	United Nations Children’s Fund
WHO	World Health Organisation

## **APPENDIX 5: EXPLANATION OF WORDS AND TERMS**

- **Attitude** *“An attitude is a relatively enduring organisation of beliefs around an object or situation predisposing one to respond in some preferential manner”* [International Encyclopaedia of Social Sciences, Ingstad 1995: 253]  
*“a behaviour representative of feeling or conviction”*  
*“ a persistent disposition to act either positively or negatively toward a person, group or object, situation or value.*  
*“A disposition that is primarily grounded in affect and emotion and is expressive of opinion rather than belief”. [Websters Dictionary 1971:141]*
- **Community** *“All people have an understanding of themselves as belonging to a larger group, defined in geographical, cultural, political, religious or historical terms or mixtures of these. This larger group will constitute a community.”* [Jareg 1994: 6]
- **Cost-efficiency** *“Cost-efficiency is a state where the cost of producing any given output is minimised and the utility of individual preferences is maximised.”* [Hägström 1997: 4]
- **Disability** *“The term disability summarises a great number of different functional limitations occurring in any population in any country of the world. People may e disabled by physical, intellectual or sensory impairment, medical conditions or medical illness. Such impairments, conditions or illness may be permanent or transitory in nature. [UNICEF 1998; 660]*
- **Empowerment** *“ Empowerment is a process in which an individual or a system s given power or authority. [Oxford English Dictionary 1978]*
- **Equalisation of opportunities** *“The process through which the various systems of society and the environment, such as services, activities, information and documentation are made available to all, particularly to persons with disabilities.”* [UNICEF 1998: 661]
- **Equal rights** *“ The principle of equal right implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. [UNICEF 1998: 661]*
- **Handicap** *“ The term handicap means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with a disability and the environment. The purpose of this term is to emphasise the focus on the shortcomings in the environment and in many organised activities in society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms. [UNICEF 1998: 660]*
- **Impairment** *“Any loss or abnormality of a psychological, or anatomical structure or function”. [WHO ICIDH 1980]*

- **Integration** “ *The process of bringing about or achieving equal membership of a population or social group; removal or absence of discrimination against groups or people on racial or cultural grounds; desegregation.* [The new shorter Oxford English Dictionary, Oxford University Press 1993]  
*“To be within. Refers to the basic need of every individual, to belong to a family, a society or other groups”.* [Jareg 1994: 63]
- **Primary prevention** is action taken to reduce the occurrence of conditions likely to cause disability. This could be provision of good water, sanitation facilities, immunisation programs, health education, legislation to reduce accidents and diminish occupational health problems, improved general level of education etc.
- **Secondary prevention** is when a disabling disease or other condition is present. Intervention can be either directed towards preventing the development of a disability or towards attempting to reverse an existing disability through curative treatment.
- **Process** “*series of action that produce a change or development*” [Jareg 1994: 91]
- **Rehabilitation** “ *a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal- oriented activities, for instance vocational rehabilitation.*” [UNICEF 1998: 661]
- “*Goal oriented process with a time limit aimed at enabling an impaired person to reach an optimal mental, physical or social functional level. If the impairment has been present from birth we talk about **habilitation***” [Jareg 1994: 61]
- **Stigma** “*It appears that stigmatisation occurs only when the social control component is imposed, or when the undesired differentness leads to some restriction in physical and social mobility and access to opportunities that allow an individual to develop his or her potential.*” [Davis 1997: 227]



## **APPENDIX 6: ORGANISATIONS INVOLVED IN THE PALESTINIAN CBR-PROGRAM**

### **National level**

#### **National Bodies**

- PA: Ministries of Youth, Social Welfare, Health
- Central national committee for Rehabilitation
- General Union of Disabled
- Federation of Sports for Disabled

#### **Specialised Institutions**

- Abu Rayya Centre for Spinal Cord
- Jerusalem Centre for Disabled Children
- Bethlehem Arab Society

### **Intermediate level**

#### **Training and research**

- Bethlehem University
- Birzeit University

#### **Inclusive education**

- Ministry of Education
- Nahda Special Education Centre

#### **Development of Specialized Rehabilitation Services**

- Ministry of Social affairs
- Non Governmental Organisations

### **Community level- Networks of NGOs'**

#### **Gaza Regional Committee**

- Red Crescent Gaza
- YMCA
- UNRWA, United Nations Relief Work Organisation
- UPMRC
- NECC
- Women Committees
- Blood Bank

#### **North Regional Committee**

- Union of Medical Relief Committee
- Patient's Friend Society in Jenin
- Red Crescent Nablus

#### **Central Regional Committee**

- Patient's Friend Society in Ramallah
- Health Services Council

#### **South Regional Committee**

- Bethlehem Arab Society
- Union of Health Work Committee
- Red Crescent Hebron

[Diakonia 1999]

## **APPENDIX 7: GUIDING PRINCIPLES AND APPROACH OF THE PALESTINIAN CBR-PROGRAM**

### ***At the community level***

- *Capacity building of grass root organisations to provide primary services for persons with disability.*
- *Support the development of integrated, multi-sectoral, multidimensional models that are realistic, built on community resources, relevant and provide a potential for replication and have the potential to contribute to national policy development.*
- *Empowerment of local communities and disabled persons to address the problem of disability in their community awareness raising*
- *Support community education to promote positive attitudes and raise awareness*

### ***At the regional level***

- *Strengthen structures, programs, associations and unions, which support implementation of rehabilitation activities at the community level.*
- *Support regional planning process and enhance the development of training capacity and resources.*
- *Support data collection/research activities to contribute to policy development and national planning.*
- *Promote co-operation, co-ordination and networking among organisations from multi sectoral backgrounds.*
- *Support the development of effective and efficient referral systems and the upgrading of specialised services at this level.*

### ***At the national level***

- *Support specialised rehabilitation services.*
- *Support policy development and national planning for disability and rehabilitation.*
- *Capacity building and technical assistance to national bodies and activities that promote the rights and needs of disabled persons.*
- *Support legislation in the best interest of persons with disabilities.*

[Diakonia 1999: 7]

## **APPENDIX 8: ETHICAL CONSIDERATIONS**

(A modified version of the Helsinki-declaration).

### ***The demands of honesty, objectivity and publicity***

The researchers should openly report the results and will not deliberately distort the results so that these may be misinterpreted.

### ***The demands of quality***

The research results can influence health and social policy development in Palestine. The researcher will therefore need to pay special attention to choice of methods and make a broad analysis of results as a basis for future decision-making, and clarify uncertainties about the results before political actions are taken.

### ***Vulnerable groups- the demands for justice***

The focus on vulnerable group's access to service and the quality of care in relation to this group will be of a major concern of the study. The research should attempt to avoid creating unrealistic hopes of assistance.

### ***Participation and the demand to be informed***

The central theme is related to community participation. This focus will also be maintained in the planning, implementation and feed back from the research. Thus, the community will need to be acquainted with the research model, participate in the study where practically possible, and get access to the results of the research. People's wish not to participate should equally be respected.

### ***Relevance and essential***

The research topic and the focus on problem identification should be of such a nature that new knowledge should lead to a better health and social service for the benefit of all members of the community.

### ***Focus on applied research***

The research will focus on topics and strategies relevant to the practice of health and social service and lead to "practical recommendations that can immediately be transferred into meaningful action"

### ***Data registers and other stored data on individuals***

Proper routines on handling and cancellation of data will be developed with the aim of protecting the individuals who have participated in the study.

[Jareg 1997: 111, Adapted version]

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This is a resource list, a list of literature that have been searched during time of the research, but that has not been directly referred to in the Master-thesis.

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## **APPENDIX 10: THE UNIVERSAL DECLARATION OF HUMAN RIGHTS**

Adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948

### ***Article 1.***

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

### ***Article 2.***

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

### ***Article 3.***

Everyone has the right to life, liberty and security of person.

### ***Article 4.***

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

### ***Article 5.***

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

### ***Article 6.***

Everyone has the right to recognition everywhere as a person before the law.

### ***Article 7.***

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

### ***Article 8.***

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

### ***Article 9.***

No one shall be subjected to arbitrary arrest, detention or exile.

### ***Article 10.***

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

### ***Article 11.***

- (1) Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.
- (2) No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

### ***Article 12.***

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

### ***Article 13.***

- (1) Everyone has the right to freedom of movement and residence within the borders of each state.
- (2) Everyone has the right to leave any country, including his own, and to return to his country.

### ***Article 14.***

- (1) Everyone has the right to seek and to enjoy in other countries asylum from persecution.
- (2) This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

### ***Article 15.***

- (1) Everyone has the right to a nationality.

- (2) No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

**Article 16.**

- (1) Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
- (2) Marriage shall be entered into only with the free and full consent of the intending spouses.
- (3) The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

**Article 17.**

- (1) Everyone has the right to own property alone as well as in association with others.
- (2) No one shall be arbitrarily deprived of his property.

**Article 18.**

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

**Article 19.**

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

**Article 20.**

- (1) Everyone has the right to freedom of peaceful assembly and association.
- (2) No one may be compelled to belong to an association.

**Article 21.**

- (1) Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
- (2) Everyone has the right of equal access to public service in his country.
- (3) The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

**Article 22.**

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

**Article 23.**

- (1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
- (2) Everyone, without any discrimination, has the right to equal pay for equal work.
- (3) Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
- (4) Everyone has the right to form and to join trade unions for the protection of his interests.

**Article 24.**

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

**Article 25.**

- (1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his



family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

*Article 26.*

(1) Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

(2) Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

(3) Parents have a prior right to choose the kind of education that shall be given to their children.

*Article 27.*

(1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

(2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

*Article 28.*

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

*Article 29.*

(1) Everyone has duties to the community in which alone the free and full development of his personality is possible.

(2) In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

(3) These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

*Article 30.*

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

## **APPENDIX 11; THE CONVENTION ON THE RIGHTS OF THE CHILD**

**Adopted and opened for signature, ratification and accession by  
General Assembly resolution 44/25  
of 20 November 1989**

**entry into force 2 September 1990, in accordance with article 49**

### **PART I**

#### **Article 1**

For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.

#### **Article 2**

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.
2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

#### **Article 3**

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

#### **Article 4**

States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation.

#### **Article 5**

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

#### **Article 6**

1. States Parties recognize that every child has the inherent right to life.
2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

#### **Article 7**

1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.
2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless.

#### **Article 8**

1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.
2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.

#### **Article 9**

1. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.
2. In any proceedings pursuant to paragraph 1 of the present article, all interested parties shall be given an opportunity to participate in the proceedings and make their views known.
3. States Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's

best interests. 4. Where such separation results from any action initiated by a State Party, such as the detention, imprisonment, exile, deportation or death (including death arising from any cause while the person is in the custody of the State) of one or both parents or of the child, that State Party shall, upon request, provide the parents, the child or, if appropriate, another member of the family with the essential information concerning the whereabouts of the absent member(s) of the family unless the provision of the information would be detrimental to the well-being of the child. States Parties shall further ensure that the submission of such a request shall of itself entail no adverse consequences for the person(s) concerned.

#### **Article 10**

1. In accordance with the obligation of States Parties under article 9, paragraph 1, applications by a child or his or her parents to enter or leave a State Party for the purpose of family reunification shall be dealt with by States Parties in a positive, humane and expeditious manner. States Parties shall further ensure that the submission of such a request shall entail no adverse consequences for the applicants and for the members of their family.
2. A child whose parents reside in different States shall have the right to maintain on a regular basis, save in exceptional circumstances personal relations and direct contacts with both parents. Towards that end and in accordance with the obligation of States Parties under article 9, paragraph 1, States Parties shall respect the right of the child and his or her parents to leave any country, including their own, and to enter their own country. The right to leave any country shall be subject only to such restrictions as are prescribed by law and which are necessary to protect the national security, public order (ordre public), public health or morals or the rights and freedoms of others and are consistent with the other rights recognized in the present Convention.

#### **Article 11**

1. States Parties shall take measures to combat the illicit transfer and non-return of children abroad.
2. To this end, States Parties shall promote the conclusion of bilateral or multilateral agreements or accession to existing agreements.

#### **Article 12**

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

#### **Article 13**

1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.
2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:
  - (a) For respect of the rights or reputations of others; or
  - (b) For the protection of national security or of public order (ordre public), or of public health or morals.

#### **Article 14**

1. States Parties shall respect the right of the child to freedom of thought, conscience and religion.
2. States Parties shall respect the rights and duties of the parents and, when applicable, legal guardians, to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.
3. Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health or morals, or the fundamental rights and freedoms of others.

#### **Article 15**

1. States Parties recognize the rights of the child to freedom of association and to freedom of peaceful assembly.
2. No restrictions may be placed on the exercise of these rights other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.

#### **Article 16**

1. No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.
2. The child has the right to the protection of the law against such interference or attacks.

#### **Article 17**

States Parties recognize the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health. To this end, States Parties shall:

- (a) Encourage the mass media to disseminate information and material of social and cultural benefit to the child and in accordance with the spirit of article 29;
- (b) Encourage international co-operation in the production, exchange and dissemination of such information and material from a diversity of cultural, national and international sources;
- (c) Encourage the production and dissemination of children's books;
- (d) Encourage the mass media to have particular regard to the linguistic needs of the child who belongs to a minority group or who is indigenous;
- (e) Encourage the development of appropriate guidelines for the protection of the child from information and material injurious to his or her well-being, bearing in mind the provisions of articles 13 and 18.

**Article 18**

1. States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.
2. For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.
3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

**Article 19**

1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.
2. Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement.

**Article 20**

1. A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.
2. States Parties shall in accordance with their national laws ensure alternative care for such a child.
3. Such care could include, inter alia, foster placement, kafalah of Islamic law, adoption or if necessary placement in suitable institutions for the care of children. When considering solutions, due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic background.

**Article 21**

States Parties that recognize and/or permit the system of adoption shall ensure that the best interests of the child shall be the paramount consideration and they shall:

- (a) Ensure that the adoption of a child is authorized only by competent authorities who determine, in accordance with applicable law and procedures and on the basis of all pertinent and reliable information, that the adoption is permissible in view of the child's status concerning parents, relatives and legal guardians and that, if required, the persons concerned have given their informed consent to the adoption on the basis of such counselling as may be necessary;
- (b) Recognize that inter-country adoption may be considered as an alternative means of child's care, if the child cannot be placed in a foster or an adoptive family or cannot in any suitable manner be cared for in the child's country of origin;
- (c) Ensure that the child concerned by inter-country adoption enjoys safeguards and standards equivalent to those existing in the case of national adoption;
- (d) Take all appropriate measures to ensure that, in inter-country adoption, the placement does not result in improper financial gain for those involved in it;
- (e) Promote, where appropriate, the objectives of the present article by concluding bilateral or multilateral arrangements or agreements, and endeavour, within this framework, to ensure that the placement of the child in another country is carried out by competent authorities or organs.

**Article 22**

1. States Parties shall take appropriate measures to ensure that a child who is seeking refugee status or who is considered a refugee in accordance with applicable international or domestic law and procedures shall, whether unaccompanied or accompanied by his or her parents or by any other person, receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the present Convention and in other international human rights or humanitarian instruments to which the said States are Parties.
2. For this purpose, States Parties shall provide, as they consider appropriate, co-operation in any efforts by the United Nations and other competent intergovernmental organizations or non-governmental organizations co-operating with the United Nations to protect and assist such a child and to trace the parents or other members of the family of any refugee child in order to obtain information necessary for reunification with his or her family. In cases where no parents or other members of the family can be found, the child shall be accorded the same protection as any other child permanently or temporarily deprived of his or her family environment for any reason, as set forth in the present Convention.

**Article 23**

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

#### **Article 24**

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

- (a) To diminish infant and child mortality;
- (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
- (c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
- (d) To ensure appropriate pre-natal and post-natal health care for mothers;
- (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
- (f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

#### **Article 25**

States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

#### **Article 26**

1. States Parties shall recognize for every child the right to benefit from social security, including social insurance, and shall take the necessary measures to achieve the full realization of this right in accordance with their national law.

2. The benefits should, where appropriate, be granted, taking into account the resources and the circumstances of the child and persons having responsibility for the maintenance of the child, as well as any other consideration relevant to an application for benefits made by or on behalf of the child.

#### **Article 27**

1. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.

2. The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development.

3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing.

4. States Parties shall take all appropriate measures to secure the recovery of maintenance for the child from the parents or other persons having financial responsibility for the child, both within the State Party and from abroad. In particular, where the person having financial responsibility for the child lives in a State different from that of the child, States Parties shall promote the accession to international agreements or the conclusion of such agreements, as well as the making of other appropriate arrangements.

#### **Article 28**

1. States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:

- (a) Make primary education compulsory and available free to all;
- (b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;
- (c) Make higher education accessible to all on the basis of capacity by every appropriate means;
- (d) Make educational and vocational information and guidance available and accessible to all children;
- (e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.

2. States Parties shall take all appropriate measures to ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with the present Convention.

3. States Parties shall promote and encourage international cooperation in matters relating to education, in particular with a view to contributing to the elimination of ignorance and illiteracy throughout the world and facilitating access to scientific and technical knowledge and modern teaching methods. In this regard, particular account shall be taken of the needs of developing countries.

#### **Article 29**

1. States Parties agree that the education of the child shall be directed to:

- (a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;

- (b) The development of respect for human rights and fundamental freedoms, and for the principles enshrined in the Charter of the United Nations;
  - (c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his or her own;
  - (d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups and persons of indigenous origin;
  - (e) The development of respect for the natural environment.
2. No part of the present article or article 28 shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principle set forth in paragraph 1 of the present article and to the requirements that the education given in such institutions shall conform to such minimum standards as may be laid down by the State.

#### **Article 30**

In those States in which ethnic, religious or linguistic minorities or persons of indigenous origin exist, a child belonging to such a minority or who is indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture, to profess and practise his or her own religion, or to use his or her own language.

#### **Article 31**

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

#### **Article 32**

1. States Parties recognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development.
2. States Parties shall take legislative, administrative, social and educational measures to ensure the implementation of the present article. To this end, and having regard to the relevant provisions of other international instruments, States Parties shall in particular:
  - (a) Provide for a minimum age or minimum ages for admission to employment;
  - (b) Provide for appropriate regulation of the hours and conditions of employment;
  - (c) Provide for appropriate penalties or other sanctions to ensure the effective enforcement of the present article.

#### **Article 33**

States Parties shall take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances.

#### **Article 34**

States Parties undertake to protect the child from all forms of sexual exploitation and sexual abuse. For these purposes, States Parties shall in particular take all appropriate national, bilateral and multilateral measures to prevent:

- (a) The inducement or coercion of a child to engage in any unlawful sexual activity;
- (b) The exploitative use of children in prostitution or other unlawful sexual practices;
- (c) The exploitative use of children in pornographic performances and materials.

#### **Article 35**

States Parties shall take all appropriate national, bilateral and multilateral measures to prevent the abduction of, the sale of or traffic in children for any purpose or in any form.

#### **Article 36**

States Parties shall protect the child against all other forms of exploitation prejudicial to any aspects of the child's welfare.

#### **Article 37**

States Parties shall ensure that:

- (a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment. Neither capital punishment nor life imprisonment without possibility of release shall be imposed for offences committed by persons below eighteen years of age;
- (b) No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time;
- (c) Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances;
- (d) Every child deprived of his or her liberty shall have the right to prompt access to legal and other appropriate assistance, as well as the right to challenge the legality of the deprivation of his or her liberty before a court or other competent, independent and impartial authority, and to a prompt decision on any such action.

**Article 38**

1. States Parties undertake to respect and to ensure respect for rules of international humanitarian law applicable to them in armed conflicts which are relevant to the child.
2. States Parties shall take all feasible measures to ensure that persons who have not attained the age of fifteen years do not take a direct part in hostilities.
3. States Parties shall refrain from recruiting any person who has not attained the age of fifteen years into their armed forces. In recruiting among those persons who have attained the age of fifteen years but who have not attained the age of eighteen years, States Parties shall endeavour to give priority to those who are oldest.
4. In accordance with their obligations under international humanitarian law to protect the civilian population in armed conflicts, States Parties shall take all feasible measures to ensure protection and care of children who are affected by an armed conflict.

**Article 39**

States Parties shall take all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of: any form of neglect, exploitation, or abuse; torture or any other form of cruel, inhuman or degrading treatment or punishment; or armed conflicts. Such recovery and reintegration shall take place in an environment which fosters the health, self-respect and dignity of the child.

**Article 40**

1. States Parties recognize the right of every child alleged as, accused of, or recognized as having infringed the penal law to be treated in a manner consistent with the promotion of the child's sense of dignity and worth, which reinforces the child's respect for the human rights and fundamental freedoms of others and which takes into account the child's age and the desirability of promoting the child's reintegration and the child's assuming a constructive role in society.
2. To this end, and having regard to the relevant provisions of international instruments, States Parties shall, in particular, ensure that:
  - (a) No child shall be alleged as, be accused of, or recognized as having infringed the penal law by reason of acts or omissions that were not prohibited by national or international law at the time they were committed;
  - (b) Every child alleged as or accused of having infringed the penal law has at least the following guarantees:
    - (i) To be presumed innocent until proven guilty according to law;
    - (ii) To be informed promptly and directly of the charges against him or her, and, if appropriate, through his or her parents or legal guardians, and to have legal or other appropriate assistance in the preparation and presentation of his or her defence;
    - (iii) To have the matter determined without delay by a competent, independent and impartial authority or judicial body in a fair hearing according to law, in the presence of legal or other appropriate assistance and, unless it is considered not to be in the best interest of the child, in particular, taking into account his or her age or situation, his or her parents or legal guardians;
    - (iv) Not to be compelled to give testimony or to confess guilt; to examine or have examined adverse witnesses and to obtain the participation and examination of witnesses on his or her behalf under conditions of equality;
    - (v) If considered to have infringed the penal law, to have this decision and any measures imposed in consequence thereof reviewed by a higher competent, independent and impartial authority or judicial body according to law;
    - (vi) To have the free assistance of an interpreter if the child cannot understand or speak the language used;
    - (vii) To have his or her privacy fully respected at all stages of the proceedings.
3. States Parties shall seek to promote the establishment of laws, procedures, authorities and institutions specifically applicable to children alleged as, accused of, or recognized as having infringed the penal law, and, in particular:
  - (a) The establishment of a minimum age below which children shall be presumed not to have the capacity to infringe the penal law;
  - (b) Whenever appropriate and desirable, measures for dealing with such children without resorting to judicial proceedings, providing that human rights and legal safeguards are fully respected.
4. A variety of dispositions, such as care, guidance and supervision orders; counselling; probation; foster care; education and vocational training programmes and other alternatives to institutional care shall be available to ensure that children are dealt with in a manner appropriate to their well-being and proportionate both to their circumstances and the offence.

**Article 41**

Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of the child and which may be contained in:

- (a) The law of a State party; or
- (b) International law in force for that State.

**PART II**

**Article 42**

States Parties undertake to make the principles and provisions of the Convention widely known, by appropriate and active means, to adults and children alike.

**Article 43**

1. For the purpose of examining the progress made by States Parties in achieving the realization of the obligations undertaken in the present Convention, there shall be established a Committee on the Rights of the Child, which shall carry out the functions hereinafter provided.
2. The Committee shall consist of ten experts of high moral standing and recognized competence in the field covered by this Convention. The members of the Committee shall be elected by States Parties from among their nationals and shall serve in their personal capacity, consideration being given to equitable geographical distribution, as well as to the principal legal systems.
3. The members of the Committee shall be elected by secret ballot from a list of persons nominated by States Parties. Each State Party may nominate one person from among its own nationals.

4. The initial election to the Committee shall be held no later than six months after the date of the entry into force of the present Convention and thereafter every second year. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to States Parties inviting them to submit their nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating States Parties which have nominated them, and shall submit it to the States Parties to the present Convention.
5. The elections shall be held at meetings of States Parties convened by the Secretary-General at United Nations Headquarters. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.
6. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election if renominated. The term of five of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these five members shall be chosen by lot by the Chairman of the meeting.
7. If a member of the Committee dies or resigns or declares that for any other cause he or she can no longer perform the duties of the Committee, the State Party which nominated the member shall appoint another expert from among its nationals to serve for the remainder of the term, subject to the approval of the Committee.
8. The Committee shall establish its own rules of procedure.
9. The Committee shall elect its officers for a period of two years.
10. The meetings of the Committee shall normally be held at United Nations Headquarters or at any other convenient place as determined by the Committee. The Committee shall normally meet annually. The duration of the meetings of the Committee shall be determined, and reviewed, if necessary, by a meeting of the States Parties to the present Convention, subject to the approval of the General Assembly.
11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention.
12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide.

#### **Article 44**

1. States Parties undertake to submit to the Committee, through the Secretary-General of the United Nations, reports on the measures they have adopted which give effect to the rights recognized herein and on the progress made on the enjoyment of those rights:
  - (a) Within two years of the entry into force of the Convention for the State Party concerned;
  - (b) Thereafter every five years.
2. Reports made under the present article shall indicate factors and difficulties, if any, affecting the degree of fulfilment of the obligations under the present Convention. Reports shall also contain sufficient information to provide the Committee with a comprehensive understanding of the implementation of the Convention in the country concerned.
3. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports submitted in accordance with paragraph 1 (b) of the present article, repeat basic information previously provided.
4. The Committee may request from States Parties further information relevant to the implementation of the Convention.
5. The Committee shall submit to the General Assembly, through the Economic and Social Council, every two years, reports on its activities.
6. States Parties shall make their reports widely available to the public in their own countries.

#### **Article 45**

In order to foster the effective implementation of the Convention and to encourage international co-operation in the field covered by the Convention:

- (a) The specialized agencies, the United Nations Children's Fund, and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies, the United Nations Children's Fund and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite the specialized agencies, the United Nations Children's Fund, and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities;
- (b) The Committee shall transmit, as it may consider appropriate, to the specialized agencies, the United Nations Children's Fund and other competent bodies, any reports from States Parties that contain a request, or indicate a need, for technical advice or assistance, along with the Committee's observations and suggestions, if any, on these requests or indications;
- (c) The Committee may recommend to the General Assembly to request the Secretary-General to undertake on its behalf studies on specific issues relating to the rights of the child;
- (d) The Committee may make suggestions and general recommendations based on information received pursuant to articles 44 and 45 of the present Convention. Such suggestions and general recommendations shall be transmitted to any State Party concerned and reported to the General Assembly, together with comments, if any, from States Parties.

### **PART III**

#### **Article 46**

The present Convention shall be open for signature by all States.



**Article 47**

The present Convention is subject to ratification. Instruments of ratification shall be deposited with the Secretary-General of the United Nations.

**Article 48**

The present Convention shall remain open for accession by any State. The instruments of accession shall be deposited with the Secretary-General of the United Nations.

**Article 49**

1. The present Convention shall enter into force on the thirtieth day following the date of deposit with the Secretary-General of the United Nations of the twentieth instrument of ratification or accession.
2. For each State ratifying or acceding to the Convention after the deposit of the twentieth instrument of ratification or accession, the Convention shall enter into force on the thirtieth day after the deposit by such State of its instrument of ratification or accession.

**Article 50**

1. Any State Party may propose an amendment and file it with the Secretary-General of the United Nations. The Secretary-General shall thereupon communicate the proposed amendment to States Parties, with a request that they indicate whether they favour a conference of States Parties for the purpose of considering and voting upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of States Parties present and voting at the conference shall be submitted to the General Assembly for approval.
2. An amendment adopted in accordance with paragraph 1 of the present article shall enter into force when it has been approved by the General Assembly of the United Nations and accepted by a two-thirds majority of States Parties.
3. When an amendment enters into force, it shall be binding on those States Parties which have accepted it, other States Parties still being bound by the provisions of the present Convention and any earlier amendments which they have accepted.

**Article 51**

1. The Secretary-General of the United Nations shall receive and circulate to all States the text of reservations made by States at the time of ratification or accession.
2. A reservation incompatible with the object and purpose of the present Convention shall not be permitted.
3. Reservations may be withdrawn at any time by notification to that effect addressed to the Secretary-General of the United Nations, who shall then inform all States. Such notification shall take effect on the date on which it is received by the Secretary-General.

**Article 52**

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. Denunciation becomes effective one year after the date of receipt of the notification by the Secretary-General.

**Article 53**

The Secretary-General of the United Nations is designated as the depositary of the present Convention.

**Article 54**

The original of the present Convention, of which the Arabic, Chinese, English, French, Russian and Spanish texts are equally authentic, shall be deposited with the Secretary-General of the United Nations.  
IN WITNESS THEREOF the undersigned plenipotentiaries, being duly authorized thereto by their respective governments, have signed the present Convention.

## **APPENDIX 12: THE LAW OF THE RIGHTS OF THE DISABLED**

Palestinian Legislative Council, October 10th. 1999.

### **First Chapter: Definitions and General Laws**

#### **Article 1:**

In implementing these laws, the following words will have the specific meanings mentioned below:

*The Ministry:* The Ministry of Social Affairs

*The Minister:* The Minister of Social Affairs

*The Disabled:* The person who has a permanent partial or complete disability, in his senses or physical, psychological or mental capabilities so that the person is incapable of fulfilling his daily normal needs in the fashion that the not disabled are capable of.

*The Disabled Card:* The card that defines the Service Package that the disabled is entitled to in the framework of a planned program.

*Rehabilitation:* The total of all services, activities and the social, psychological, medical, educational, pedagogical and vocational circumstances which enable the disabled person to pursue their lives in complete independence and dignity.

*Protected Workshops:* The centres in which persons with extreme mental disabilities are given work and shelter.

*The Public Place:* Every building, tunnel or path or any other place where public service is rendered.

*Adaptation:* Making public places and facilities accessible to the disabled.

#### **Article 2:**

The disabled have the right to enjoy a free and dignified life and to enjoy all services. He/She has the same rights as other citizens. He/She also has duties that are limited to his/her capabilities. His/Her disability should not be the reason to withhold his/her rights.

#### **Article 3:**

The State takes upon itself to protect the disabled rights and to facilitate to the disabled the achievement of these rights. The Ministry, in co-operation with involved parties, is preparing an Awareness Program to serve the disabled, his/her family and local surroundings, regarding all aspects pertaining to all the rights that are contained under this law.

#### **Article 4:**

According to the sub-laws of the law, the disabled have the right to create their own organisations and societies.

#### **Article 5:**

The State takes upon itself to offer all sort of rehabilitation to the disabled according to the extent of his/her disability and with a personal share of not exceeding 25% of the total cost of rehabilitation from the disabled person. Those disabled as a result of resisting occupation are exempt from the share.

#### **Article 6:**

According to the sub-laws of the law the following are exempt from fees, customs and taxes:

1. All educational and medical material as well as transportation to and from schools and licensed disabled institutions.
2. All personal transportation means used by disabled individuals.

#### **Article 7:**

The Ministry demands yearly reports and plans of Disabled Services from governmental institutions.

#### **Article 8:**

According to the sub-laws of the law, and in co-ordination with the Ministry, the respective ministry will bestow and issue the necessary technical licenses to the non-governmental sector for the disabled so as it could conduct services, programs and activities, which will be monitored by the Ministry.

**Article 9:**

The State has to pass regulations that guarantee the protection of the disabled from all kinds of violence, abuse and inequality.

**Second Chapter: Private Laws**

**Article 10:**

The Ministry is responsible for conducting care and rehabilitation of the disabled with relevant parties and in the following fields:

**1. The Social Field**

- One) Defining the nature of the disability and its extent and effect on the family of the disabled as well as offering suitable services.
- Two) Rendering services such as care, relief, training, education to the disabled as well as rendering priority to the disabled regarding family development.
- Three) Rendering social care and shelter to the extremely disabled which have no one to provide for them.
- Four) Supporting the program: Protective Workshop
- Five) Issuing the Disabled Card

**2. The Medical Field:**

- One) Diagnosing and classifying the level of disability
- Two) Guaranteeing free medical services included in the governmental medical insurance for the disabled and their family.
- Three) Rendering and developing early disability discovery
- Four) Making available instruments and medical devices necessary in assisting the disabled (Article 5 of this law)
- Five) Rendering preventive and medical services aimed at reducing disabilities in the society.

**3. The Educational Field:**

- One) Guaranteeing the right of the disabled to equal opportunity to enrol in educational institutions and universities in the framework of the implemented curricula in those institutions.
- Two) Rendering aptitude diagnosis to define the extent of the disability.
- Three) Making available curricula and pedagogical and educational means and suitable facilitation.
- Four) Rendering all sorts and levels of education to the disabled according to their needs.
- Five) Training teachers to teach the disabled according to their disability.

**4. The Rehabilitation and Work Field:**

- One) Training cadres to work with the disabled with different levels of disability.
- Two) Guaranteeing the right to enrol in rehabilitation and vocational training facilities on the basis of equal opportunity.
- Three) Committing governmental and non-governmental institutions to absorb no less than 5% of its work force from the disabled. The working place has to be adapted to their needs.

**5. The Leisure and Sport Field:**

- One) Making available sport and leisure facilities to the disabled as well as adapting playgrounds, halls, camps, clubs and their facilities to the disabled needs and providing them with the necessary equipment.
- Two) Supporting the disabled participation in national and international sport programs.
- Three) Reducing entrance fees to cultural, leisure, archaeological and governmental institutions by 50%.

**6. The Field of Public Awareness:**

- One) Conducting public awareness campaigns on all sorts of disabilities, their causes, consequences and needs.

Two) Publishing information and statistics pertaining to prevention in the hope of decreasing disabilities in the society.

Three) Publishing general awareness instructions aiming at reforming the perception of the disabled by the society and assimilating them into the society.

Four) Using sign language on TV.

**Article 11:**

The State is working on incorporating sign language in governmental institutions.

**Third Chapter: Adapting Public Places to Disabled**

**Article 12:**

Adaptation aims at realising a suitable environment for the disabled which guarantees accessibility, independence, freedom of movement and transportation as well as the use of public facilities.

**Article 13:**

One) Adaptation is obligatory for relevant parties except:

- If it threatens historical and archaeological aspect of the public place.
- If it endangers the security of the public place.
- In all the upper cases, the relevant parties have to find suitable substitutes to guarantee public use by the disabled.

**Article 14:**

Both the Ministry of Higher Education and the Ministry of Education have to secure a suitable environment adapted to the needs of the disabled at schools, colleges and universities.

**Article 15:**

The Ministry of Local Government, in co-ordination with the relevant parties, takes responsibility for obliging public and private institutions to abide by the technical and architectural specifications that have to be made available in old and new public building to serve the disabled.

**Article 16:**

The Ministry of Transportation is working on adapting a suitable environment to facilitate the mobility of the disabled in addition to granting them and their companion's special discounts in public transportation.

**Article 17:**

The Ministry of Transportation is also facilitating the use of communication facilities and devices by the disabled.

**Fourth Chapter: Final sub-laws**

**Article 18:**

Any article, which contradicts the sub-laws of the law, is cancelled.

**Article 19:**

The Council of Ministers will issue the regulations pertaining to executing the articles of this law.

**Article 20:**

All involved parties are to abide and implement this law which will be valid at the time of its publishing in the local newspaper.

Issued in Gaza City on 09.08.99

*Yasser Arafat, Head of the Executive Committee of the PLO, President of the Palestinian National Authority*

[ Söderlind 2000]

## **APPENDIX 13: THE STANDARD RULES ON THE EQUALISATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES**

UN, 20 December 1993: A/RES/48/96

### **I. PRECONDITIONS FOR EQUAL PARTICIPATION**

#### **Rule 1. Awareness-raising**

States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.

1. States should ensure that responsible authorities distribute up-to-date information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public. Information to persons with disabilities should be presented in accessible form.
2. States should initiate and support information campaigns concerning persons with disabilities and disability policies, conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation.
3. States should encourage the portrayal of persons with disabilities by the mass media in a positive way; organizations of persons with disabilities should be consulted on this matter.
4. States should ensure that public education programmes reflect in all their aspects the principle of full participation and equality.
5. States should invite persons with disabilities and their families and organizations to participate in public education programmes concerning disability matters.
6. States should encourage enterprises in the private sector to include disability issues in all aspects of their activity.
7. States should initiate and promote programmes aimed at raising the level of awareness of persons with disabilities concerning their rights and potential. Increased self-reliance and empowerment will assist persons with disabilities to take advantage of the opportunities available to them.
8. Awareness-raising should be an important part of the education of children with disabilities and in rehabilitation programmes. Persons with disabilities could also assist one another in awareness-raising through the activities of their own organizations.
9. Awareness-raising should be part of the education of all children and should be a component of teacher-training courses and training of all professionals.

#### **Rule 2. Medical care**

States should ensure the provision of effective medical care to persons with disabilities.

1. States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level.
2. Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.
3. States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.

4. States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.
5. States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.
6. States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.

### **Rule 3. Rehabilitation\***

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

1. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality.
2. Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.
3. All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.
4. Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves.
5. All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form.
6. Persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counsellors.
7. States should draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programmes.

### **Rule 4. Support services**

States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.

1. States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with disabilities, as important measures to achieve the equalization of opportunities.
2. States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them.
3. To achieve this, generally available technical know-how should be utilized. In States where high-technology industry is available, it should be fully utilized to improve the standard and effectiveness of assistive devices and equipment. It is important to stimulate the development and production of simple and inexpensive devices, using local material and local production facilities when possible. Persons with disabilities themselves could be involved in the production of those devices.
4. States should recognize that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility. This may mean that assistive devices and equipment should

be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them.

5. In rehabilitation programmes for the provision of assistive devices and equipment, States should consider the special requirements of girls and boys with disabilities concerning the design, durability and age-appropriateness of assistive devices and equipment.

6. States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities.

7. Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

## **II. TARGET AREAS FOR EQUAL PARTICIPATION**

### **Rule 5. Accessibility**

States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society. For persons with disabilities of any kind, States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication.

#### **(a) Access to the physical environment**

1. States should initiate measures to remove the obstacles to participation in the physical environment. Such measures should be to develop standards and guidelines and to consider enacting legislation to ensure accessibility to various areas in society, such as housing, buildings, public transport services and other means of transportation, streets and other outdoor environments.

2. States should ensure that architects, construction engineers and others who are professionally involved in the design and construction of the physical environment have access to adequate information on disability policy and measures to achieve accessibility.

3. Accessibility requirements should be included in the design and construction of the physical environment from the beginning of the designing process.

4. Organizations of persons with disabilities should be consulted when standards and norms for accessibility are being developed. They should also be involved locally from the initial planning stage when public construction projects are being designed, thus ensuring maximum accessibility.

#### **(b) Access to information and communication**

5. Persons with disabilities and, where appropriate, their families and advocates should have access to full information on diagnosis, rights and available services and programmes, at all stages. Such information should be presented in forms accessible to persons with disabilities.

6. States should develop strategies to make information services and documentation accessible for different groups of persons with disabilities. Braille, tape services, large print and other appropriate technologies should be used to provide access to written information and documentation for persons with visual impairments. Similarly, appropriate technologies should be used

to provide access to spoken information for persons with auditory impairments or comprehension difficulties.

7. Consideration should be given to the use of sign language in the education of deaf children, in their families and communities. Sign language interpretation services should also be provided to facilitate the communication between deaf persons and others.

8. Consideration should also be given to the needs of people with other communication disabilities.
9. States should encourage the media, especially television, radio and newspapers, to make their services accessible.
10. States should ensure that new computerized information and service systems offered to the general public are either made initially accessible or are adapted to be made accessible to persons with disabilities.
11. Organizations of persons with disabilities should be consulted when measures to make information services accessible are being developed.

#### **Rule 6. Education**

States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system.

1. General educational authorities are responsible for the education of persons with disabilities in integrated settings. Education for persons with disabilities should form an integral part of national educational planning, curriculum development and school organization.
2. Education in mainstream schools presupposes the provision of interpreter and other appropriate support services. Adequate accessibility and support services, designed to meet the needs of persons with different disabilities, should be provided.
3. Parent groups and organizations of persons with disabilities should be involved in the education process at all levels.
4. In States where education is compulsory it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe.
5. Special attention should be given in the following areas:
  - (a) Very young children with disabilities;
  - (b) Pre-school children with disabilities;
  - (c) Adults with disabilities, particularly women.
6. To accommodate educational provisions for persons with disabilities in the mainstream, States should:
  - (a) Have a clearly stated policy, understood and accepted at the school level and by the wider community;
  - (b) Allow for curriculum flexibility, addition and adaptation;
  - (c) Provide for quality materials, ongoing teacher training and support teachers.
7. Integrated education and community-based programmes should be seen as complementary approaches in providing cost-effective education and training for persons with disabilities. National community-based programmes should encourage communities to use and develop their resources to provide local education to persons with disabilities.
8. In situations where the general school system does not yet adequately meet the needs of all persons with disabilities, special education may be considered. It should be aimed at preparing students for education in the general school system. The quality of such education should reflect the same standards and ambitions as general education and should be closely linked to it. At a minimum, students with disabilities should be afforded the same portion of educational resources as students without disabilities. States should aim for the gradual integration of special education services into mainstream education. It is acknowledged that in some instances special education may currently be considered to be the most appropriate form of education for some students with disabilities.
9. Owing to the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in schools for such persons or special classes and units in mainstream schools. At the initial



stage, in particular, special attention needs to be focused on culturally sensitive instruction that will result in effective communication skills and maximum independence for people who are deaf or deaf/blind.

#### **Rule 7. Employment**

States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market.

1. Laws and regulations in the employment field must not discriminate against persons with disabilities and must not raise obstacles to their employment.
2. States should actively support the integration of persons with disabilities into open employment. This active support could occur through a variety of measures, such as vocational training, incentive-oriented quota schemes, reserved or designated employment, loans or grants for small business, exclusive contracts or priority production rights, tax concessions, contract compliance or other technical or financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities.
3. States' action programmes should include:
  - (a) Measures to design and adapt workplaces and work premises in such a way that they become accessible to persons with different disabilities;
  - (b) Support for the use of new technologies and the development and production of assistive devices, tools and equipment and measures to facilitate access to such devices and equipment for persons with disabilities to enable them to gain and maintain employment;
  - (c) Provision of appropriate training and placement and ongoing support such as personal assistance and interpreter services.
4. States should initiate and support public awareness-raising campaigns designed to overcome negative attitudes and prejudices concerning workers with disabilities.
5. In their capacity as employers, States should create favourable conditions for the employment of persons with disabilities in the public sector.
6. States, workers' organizations and employers should cooperate to ensure equitable recruitment and promotion policies, employment conditions, rates of pay, measures to improve the work environment in order to prevent injuries and impairments and measures for the rehabilitation of employees who have sustained employment-related injuries.
7. The aim should always be for persons with disabilities to obtain employment in the open labour market. For persons with disabilities whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative. It is important that the quality of such programmes be assessed in terms of their relevance and sufficiency in providing opportunities for persons with disabilities to gain employment in the labour market.
8. Measures should be taken to include persons with disabilities in training and employment programmes in the private and informal sectors.
9. States, workers' organizations and employers should cooperate with organizations of persons with disabilities concerning all measures to create training and employment opportunities, including flexible hours, part-time work, job-sharing, self-employment and attendant care for persons with disabilities.

#### **Rule 8. Income maintenance and social security**

States are responsible for the provision of social security and income maintenance for persons with disabilities.

1. States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities. States should ensure that the provision of support takes into account the costs frequently incurred by persons with disabilities and their families as a result of the disability.
2. In countries where social security, social insurance or other social welfare schemes exist or are being developed for the general population, States should ensure that such systems do not exclude or discriminate against persons with disabilities.
3. States should also ensure the provision of income support and social security protection to individuals who undertake the care of a person with a disability.
4. Social security systems should include incentives to restore the income-earning capacity of persons with disabilities. Such systems should provide or contribute to the organization, development and financing of vocational training. They should also assist with placement services.
5. Social security programmes should also provide incentives for persons with disabilities to seek employment in order to establish or re-establish their income-earning capacity.
6. Income support should be maintained as long as the disabling conditions remain in a manner that does not discourage persons with disabilities from seeking employment. It should only be reduced or terminated when persons with disabilities achieve adequate and secure income.
7. States, in countries where social security is to a large extent provided by the private sector, should encourage local communities, welfare organizations and families to develop self-help measures and incentives for employment or employment-related activities for persons with disabilities.

#### **Rule 9. Family life and personal integrity**

States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

1. Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counselling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-care services should be made available to families which include a person with disabilities. States should remove all unnecessary obstacles to persons who want to foster or adopt a child or adult with disabilities.
2. Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.
3. States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society. The media should be encouraged to play an important role in removing such negative attitudes.
3. Persons with disabilities and their families need to be fully informed about taking precautions against sexual and other forms of abuse. Persons with disabilities are particularly vulnerable to abuse in the family, community or institutions and need to be educated on how to avoid the occurrence of abuse, recognize when abuse has occurred and report on such acts.

#### **Rule 10. Culture**

States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis.

1. States should ensure that persons with disabilities have the opportunity to utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of their community, be they in urban or rural areas. Examples of such activities are dance, music, literature, theatre, plastic arts, painting and sculpture. Particularly in developing countries, emphasis should be placed on traditional and contemporary art forms, such as puppetry, recitation and story-telling.
2. States should promote the accessibility to and availability of places for cultural performances and services, such as theatres, museums, cinemas and libraries, to persons with disabilities.
3. States should initiate the development and use of special technical arrangements to make literature, films and theatre accessible to persons with disabilities.

#### **Rule 11. Recreation and sports**

States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports.

1. States should initiate measures to make places for recreation and sports, hotels, beaches, sports arenas, gym halls, etc., accessible to persons with disabilities. Such measures should encompass support for staff in recreation and sports programmes, including projects to develop methods of accessibility, and participation, information and training programmes.
2. Tourist authorities, travel agencies, hotels, voluntary organizations and others involved in organizing recreational activities or travel opportunities should offer their services to all, taking into account the special needs of persons with disabilities. Suitable training should be provided to assist that process.
3. Sports organizations should be encouraged to develop opportunities for participation by persons with disabilities in sports activities. In some cases, accessibility measures could be enough to open up opportunities for participation. In other cases, special arrangements or special games would be needed. States should support the participation of persons with disabilities in national and international events.
4. Persons with disabilities participating in sports activities should have access to instruction and training of the same quality as other participants.
5. Organizers of sports and recreation should consult with organizations of persons with disabilities when developing their services for persons with disabilities.

#### **Rule 12. Religion**

States will encourage measures for equal participation by persons with disabilities in the religious life of their communities.

1. States should encourage, in consultation with religious authorities, measures to eliminate discrimination and make religious activities accessible to persons with disabilities.
2. States should encourage the distribution of information on disability matters to religious institutions and organizations. States should also encourage religious authorities to include information on disability policies in the training for religious professions, as well as in religious education programmes.
3. They should also encourage the accessibility of religious literature to persons with sensory impairments.
4. States and/or religious organizations should consult with organizations of persons with disabilities when developing measures for equal participation in religious activities.

### **III. IMPLEMENTATION MEASURES**

#### **Rule 13. Information and research**

States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities.

1. States should, at regular intervals, collect gender-specific statistics and other information concerning the living conditions of persons with disabilities. Such data collection could be conducted in conjunction with national censuses and household surveys and could be undertaken in close collaboration, inter alia, with universities, research institutes and organizations of persons with disabilities. The data collection should include questions on programmes and services and their use.
2. States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities. They should bear in mind the need to protect individual privacy and personal integrity.
3. States should initiate and support programmes of research on social, economic and participation issues that affect the lives of persons with disabilities and their families. Such research should include studies on the causes, types and frequencies of disabilities, the availability and efficacy of existing programmes and the need for development and evaluation of services and support measures.
4. States should develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities.
5. States should facilitate the participation of persons with disabilities in data collection and research. To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities.
6. States should support the exchange of research findings and experiences.
7. States should take measures to disseminate information and knowledge on disability to all political and administration levels within national, regional and local spheres.

#### **Rule 14. Policy-making and planning**

States will ensure that disability aspects are included in all relevant policy-making and national planning.

1. States should initiate and plan adequate policies for persons with disabilities at the national level, and stimulate and support action at regional and local levels.
2. States should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social status.
3. The needs and concerns of persons with disabilities should be incorporated into general development plans and not be treated separately.
4. The ultimate responsibility of States for the situation of persons with disabilities does not relieve others of their responsibility. Anyone in charge of services, activities or the provision of information in society should be encouraged to accept responsibility for making such programs available to persons with disabilities.
5. States should facilitate the development by local communities of programmes and measures for persons with disabilities. One way of doing this could be to develop manuals or check-lists and provide training programmes for local staff.

#### **Rule 15. Legislation**

States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities.

1. National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens. States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation.
2. Legislative action may be needed to remove conditions that may adversely affect the lives of persons with disabilities, including harassment and victimization. Any discriminatory provisions against persons with disabilities must be eliminated. National legislation should provide for appropriate sanctions in case of violations of the principles of non-discrimination.
3. National legislation concerning persons with disabilities may appear in two different forms. The rights and obligations may be incorporated in general legislation or contained in special legislation. Special legislation for persons with disabilities may be established in several ways:
  - (a) By enacting separate legislation, dealing exclusively with disability matters;
  - (b) By including disability matters within legislation on particular topics;
  - (c) By mentioning persons with disabilities specifically in the texts that serve to interpret existing legislation.A combination of those different approaches might be desirable. Affirmative action provisions may also be considered.
4. States may consider establishing formal statutory complaints mechanisms in order to protect the interests of persons with disabilities.

#### **Rule 16. Economic policies**

States have the financial responsibility for national programmes and measures to create equal opportunities for persons with disabilities.

1. States should include disability matters in the regular budgets of all national, regional and local government bodies.
2. States, non-governmental organizations and other interested bodies should interact to determine the most effective ways of supporting projects and measures relevant to persons with disabilities.
3. States should consider the use of economic measures (loans, tax exemptions, earmarked grants, special funds, and so on) to stimulate and support equal participation by persons with disabilities in society.
4. In many States it may be advisable to establish a disability development fund, which could support various pilot projects and self-help programmes at the grass-roots level.

#### **Rule 17. Coordination of work**

States are responsible for the establishment and strengthening of national coordinating committees, or similar bodies, to serve as a national focal point on disability matters.

1. The national coordinating committee or similar bodies should be permanent and based on legal as well as appropriate administrative regulation.
2. A combination of representatives of private and public organizations is most likely to achieve an intersectoral and multidisciplinary composition. Representatives could be drawn from concerned government ministries, organizations of persons with disabilities and non-governmental organizations.
3. Organizations of persons with disabilities should have considerable influence in the national coordinating committee in order to ensure proper feedback of their concerns.

4. The national coordinating committee should be provided with sufficient autonomy and resources to fulfil its responsibilities in relation to its decision-making capacities. It should report to the highest governmental level.

**Rule 18. Organizations of persons with disabilities**

States should recognize the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters.

1. States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates. States should recognize that those organizations have a role to play in the development of disability policy.
2. States should establish ongoing communication with organizations of persons with disabilities and ensure their participation in the development of government policies.
3. The role of organizations of persons with disabilities could be to identify needs and priorities, to participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, and to contribute to public awareness and to advocate change.
4. As instruments of self-help, organizations of persons with disabilities provide and promote opportunities for the development of skills in various fields, mutual support among members and information sharing.
5. Organizations of persons with disabilities could perform their advisory role in many different ways such as having permanent representation on boards of government-funded agencies, serving on public commissions and providing expert knowledge on different projects.
6. The advisory role of organizations of persons with disabilities should be ongoing in order to develop and deepen the exchange of views and information between the State and the organizations.
7. Organizations should be permanently represented on the national coordinating committee or similar bodies.
8. The role of local organizations of persons with disabilities should be developed and strengthened to ensure that they influence matters at the community level.

**Rule 19. Personnel training**

States are responsible for ensuring the adequate training of personnel, at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities.

1. States should ensure that all authorities providing services in the disability field give adequate training to their personnel.
2. In the training of professionals in the disability field, as well as in the provision of information on disability in general training programmes, the principle of full participation and equality should be appropriately reflected.
3. States should develop training programmes in consultation with organizations of persons with disabilities, and persons with disabilities should be involved as teachers, instructors or advisers in staff training programmes.
4. The training of community workers is of great strategic importance, particularly in developing countries. It should involve persons with disabilities and include the development of appropriate values, competence and technologies as well as skills which can be practised by persons with disabilities, their parents, families and members of the community.

**Rule 20. National monitoring and evaluation of disability programmes in the implementation of the Rules**

States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalization of opportunities for persons with disabilities.

1. States should periodically and systematically evaluate national disability programmes and disseminate both the bases and the results of the evaluations.
2. States should develop and adopt terminology and criteria for the evaluation of disability-related programmes and services.
3. Such criteria and terminology should be developed in close cooperation with organizations of persons with disabilities from the earliest conceptual and planning stages.
4. States should participate in international cooperation in order to develop common standards for national evaluation in the disability field. States should encourage national coordinating committees to participate also.
5. The evaluation of various programmes in the disability field should be built in at the planning stage, so that the overall efficacy in fulfilling their policy objectives can be evaluated.

**Rule 21. Technical and economic cooperation**

States, both industrialized and developing, have the responsibility to cooperate in and take measures for the improvement of the living conditions of persons with disabilities in developing countries.

1. Measures to achieve the equalization of opportunities of persons with disabilities, including refugees with disabilities, should be integrated into general development programmes.
2. Such measures must be integrated into all forms of technical and economic cooperation, bilateral and multilateral, governmental and non-governmental. States should bring up disability issues in discussions on such cooperation with their counterparts.
3. When planning and reviewing programmes of technical and economic cooperation, special attention should be given to the effects of such programmes on the situation of persons with disabilities. It is of the utmost importance that persons with disabilities and their organizations are consulted on any development projects designed for persons with disabilities.

They should be directly involved in the development, implementation and evaluation of such projects.

4. Priority areas for technical and economic cooperation should include:
  - (a) The development of human resources through the development of skills, abilities and potentials of persons with disabilities and the initiation of employment-generating activities for and of persons with disabilities;
  - (b) The development and dissemination of appropriate disability-related technologies and know-how.
5. States are also encouraged to support the formation and strengthening of organizations of persons with disabilities.
6. States should take measures to improve the knowledge of disability issues among staff involved at all levels in the administration of technical and economic cooperation programmes.

**Rule 22. International cooperation**

States will participate actively in international cooperation concerning policies for the equalization of opportunities for persons with disabilities.

1. Within the United Nations, the specialized agencies and other concerned intergovernmental organizations, States should participate in the development of disability policy.
2. Whenever appropriate, States should introduce disability aspects in general negotiations concerning standards, information exchange, development programmes, etc.
3. States should encourage and support the exchange of knowledge and experience among:
  - (a) Non-governmental organizations concerned with disability issues;

- (b) Research institutions and individual researchers involved in disability issues;
  - (c) Representatives of field programmes and of professional groups in the disability field;
  - (d) Organizations of persons with disabilities;
  - (e) National coordinating committees.
4. States should ensure that the United Nations and the specialized agencies, as well as all intergovernmental and interparliamentary bodies, at global and regional levels, include in their work the global and regional organizations of persons with disabilities.

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